

THE PARENT PROGRAMME: A PSYCHO-
EDUCATIONAL INTERVENTION FOR
PARENTS OF CHILDREN WITH AUTISM

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Abstract

Background

Having a child with autism places significant demands on parents. Few interventions address parental understanding of the meaning behind child behaviour, and the relationship this has with parental stress. Parent-mediated interventions focus on behaviour exhibited by the child and ignore parental stress. This study assesses the impact of a psycho-educational intervention, which assists parents to derive meaning from their child's behaviour.

Aims

The overall aim was to investigate if an intervention targeted exclusively at parents would:

- Reduce parent stress associated with Child Characteristics
- Reduce parent stress associated with Parenting Characteristics
- Facilitate changes in parental coping styles

Methods

A quantitative approach was adopted to evaluate the impact of the intervention. Measures of parental stress (Parenting Stress Index) and parental coping (Ways of Coping, Revised) were taken at three time intervals; prior to, at a mid-point, and at the end of the intervention.

Results

Questionnaires were completed by 71 parents and the results were computed using a repeated measures analysis of variance (ANOVA). There was a statistically significant change within the parent and child domains of the Parenting Stress Index ($p < 0.0005$), with parents showing less stress associated with interpretations of their child's behaviour, and significant changes in their use of problem-focussed coping.

Conclusion

Parent-mediated interventions that target parent characteristics associated with child behaviour, are inexpensive and have significant benefit. However, we require further research to explore the relationship between stress and coping variables in parents of children with autism to inform the future direction of intervention.

Keywords: Parents, Autism, Stress, Coping, Psycho-Educational Intervention

CHAPTER ONE

INTRODUCTION AND RESEARCH OVERVIEW

This chapter aims to provide a general introduction to the key premises involved in this study. It contains a broad overview of autism, stress and coping in parents, and behavioural family interventions. An outline of the entire dissertation is also provided including the research aims.

1.1 Background

1.1.1 *Autism*

Autism is a neuro-developmental disorder that affects approximately 116 per 10, 000 individuals, within the general population (Baird, Siminoff, Pickles, Chandler, Loucas, and Meldrum, 2006). As a pervasive, life long developmental disability autism has come to be clinically recognised through core impairments in socialisation, communication and imagination, a picture of the disability which has commonly been referred to as Wing's triad of impairment (Rutter and Schopler 1987), the term being derived from an epidemiological study by Wing and Gould (1979) in the Camberwell area of London U.K.

When we look across the population of those individuals affected by autism we observe a spectrum of disorders, with variation of the condition from person to person, and a large group showing signs of associated learning disability, a group frequently referred to as 'classically autistic' or having Kanner type autism (Kanner, 1943). Evidence of associated learning disability within the autistic population has been found in numerous studies (Wing, 1988; Frith, 1989; Happe, 1994). Steffenburg (1991) observed that in a clinic sample of 52 children, 35 of whom met the World Health Organisation ICD-10 (International Classification of Diseases, Version 10) criteria of having an Autism Spectrum Disorder (ASD), and 17 who exhibited features of an Autism Spectrum Disorder (ASD), 90% of the sample exhibited some form of neurological dysfunction, in addition to "autistic features".

In terms of cognitive ability, a significant number of individuals on the autism spectrum are described as being more able individuals, commonly referred to as having Asperger Syndrome (Asperger, 1991). In this sub group the main clinical features include: lack of empathy, naïve and one-sided interaction, impaired or

absence of ability to form friendships, pedantic repetitive speech, poor non- verbal communication, intense absorption in certain subjects and clumsy and ill-coordinated movements (Burgoine and Wing, 1983). While IQ levels and mental age vary considerably across the spectrum, all individuals classified as having autism will have difficulty in social interaction, communication and imagination often with repetitive and stereotyped behaviour, and sensory/ perceptual abnormalities.

There has been considerable debate as to the terminology used to describe the umbrella term autism, with some authors referring to Autism Spectrum Disorders, others referring to the more socially valid term Autism Spectrum Condition and more recently a return to the term autism to cover the range of behaviours observed (Baron-Cohen, 2008). The scope of this thesis does not allow for an in-depth discussion as to the merits of terminology and so the term autism will be used throughout to cover the whole of the autism spectrum including; Asperger Syndrome, Kanner Type, Infantile and High Functioning Autism.

1.1.2 Stress in Parents

Being a carer for a child with a disability is a role that extends the course of the child's lifespan (Raina, *et al.*, 2004), with a strong evidence base to suggest that bringing up a child with a disability has an association with increased parental stress (Hauser-Cram, Warfield, Shonkoff and Krauss, 2001). Moreover, how families cope with the stresses and demands of managing a child with a disability are very much dependent on family belief systems which influence adaptation and resilience (McCubbin and McCubbin 1993; Hawley and DeHaan 1996; Walsh 1998).

The trajectory of development of children with autism does not follow a uniform path (Lord, *et al.*, 2006) and thus, the changing and difficult to predict patterns of behaviour exhibited by this group of children represent a constant source of stress on the family unit. The extremely antisocial, disruptive behaviours associated with autism, such as self-injurious behaviour, tantrum and obsessive/compulsive behaviours, in themselves preclude a normal family life (Gray and Holden, 1992) and are risk factors for parental mental health (Emerson, 2003).

1.1.3 Behavioural Family Interventions

Despite the well understood challenges that parents of children with autism face, current interventions for autism are primarily targeted towards children with the disorder and the specific impairments involved. Home based interventions are generally targeted at younger children and involve training parents to deliver a programme with little consideration of the daily parenting demands involved in parenting their child. In their Cochrane Collaboration Review, *Parent Mediated Early Intervention for Young Children with Autism Spectrum Disorder*, Diggle and McConachie (2009) found that while some parent mediated interventions assessed the impact of parental knowledge, there was little attention paid to the stress experienced by parents or the emotional impact of delivering a home based intervention.

1.2 Research Overview

This study assesses the impact of a psycho-educational intervention for parents of children with autism. The intervention was developed based on the author's experience of delivering parent workshops while employed by the National Autistic Society, and review of the literature on parent-mediated interventions (Dawson, and Osterling, 1997; Prizant and Wetherby, 1998).

Psycho-education was first described by Anderson, Gerard, Hogarty and Reiss (1980) in their work with people with schizophrenia and their family members. The approach the authors described consisted of briefing patients about their illness, problem solving training, communication training, and self-assertiveness training. However, unlike other forms of intervention that solely targeted the person affected by schizophrenia, the programme included family members and emphasised their role in understanding the disease and its impact on relationships. Since this original description a number of other studies have highlighted the value of psycho-educational approaches for families of people affected by schizophrenia (Pitschel-Walz, Leucht, Bäuml, Kissling and Engel, 2001; Pilling, Bebbington and Kuipers, et al 2002; Penn and Mueser, 2004). German speaking researchers have shown particular interest in the approach and the formation of a working group to distill the central concepts involved in psycho-education formulated the following definition:

“The term psychoeducation comprises systemic, didactic-psychotherapeutic interventions, which are adequate for informing patients and their relatives about the illness and its treatment, facilitating both an understanding and personally responsible handling of the illness and supporting those afflicted in coping with the disorder.”

(Bäumel and Pitschel-Walz, 2003)

This definition highlights the importance of shared knowledge and understanding of the condition schizophrenia between the person directly affected and family members involved in the person’s care. Moreover, it introduces the concept that coping with the condition is shared and should shape the nature of psychotherapeutic intervention.

While psycho-educational approaches are discussed within the literature pertaining to schizophrenia, they are generally absent from the literature concerned with families supporting children with other non-curable neuro-developmental conditions such as autism. In contrast, many home based approaches for children with autism focus on a treatment paradigm. Such approaches target specific behaviours presented by the child for elimination and/or reduction, and parents are trained in the delivery of a behavioural programme to the child (Mesibov, Schopler, and Hearsey, 1994; Schreibman and Koegel, 1996; Connor, 1998). A more detailed discussion of some of these approaches is provided in chapter 4. A key difference between home based interventions which seek to treat autism and the psycho-educational approach evaluated in this thesis is that rather than try to eradicate behaviours presented by the child the psycho-educational approach seeks to develop parental understanding of the child’s behaviour and frame that within the child’s own expression. In doing so, the psycho-educational approach aims to assist parents in ascribing meaning to their child’s behaviour, enhance interaction and ultimately reduce parental stress.

Rather than focus extensively on objective changes in child behaviour as is the focus of most established studies of parent-mediated intervention, the study targeted parental appraisal of their child's behaviour. This was achieved by providing 2 parent workshops with accompanying manuals and 21 hours of support with a facilitator who assisted parents in identifying those behaviours which could be supported given parental and family resources. Facilitators did not provide direct instruction on how to support child behaviour, but instead used Motivational Interviewing (MI) techniques (Miller and Rollnick, 2002) as a means of exploring with parents their feelings towards addressing problem behaviours in their child. MI differs from externally-driven methods for motivating change as it does not impose change but rather supports it in a manner consistent with the parents' own values and concerns.

Figure 1 provides a broad illustrative overview of the chronology of the study.

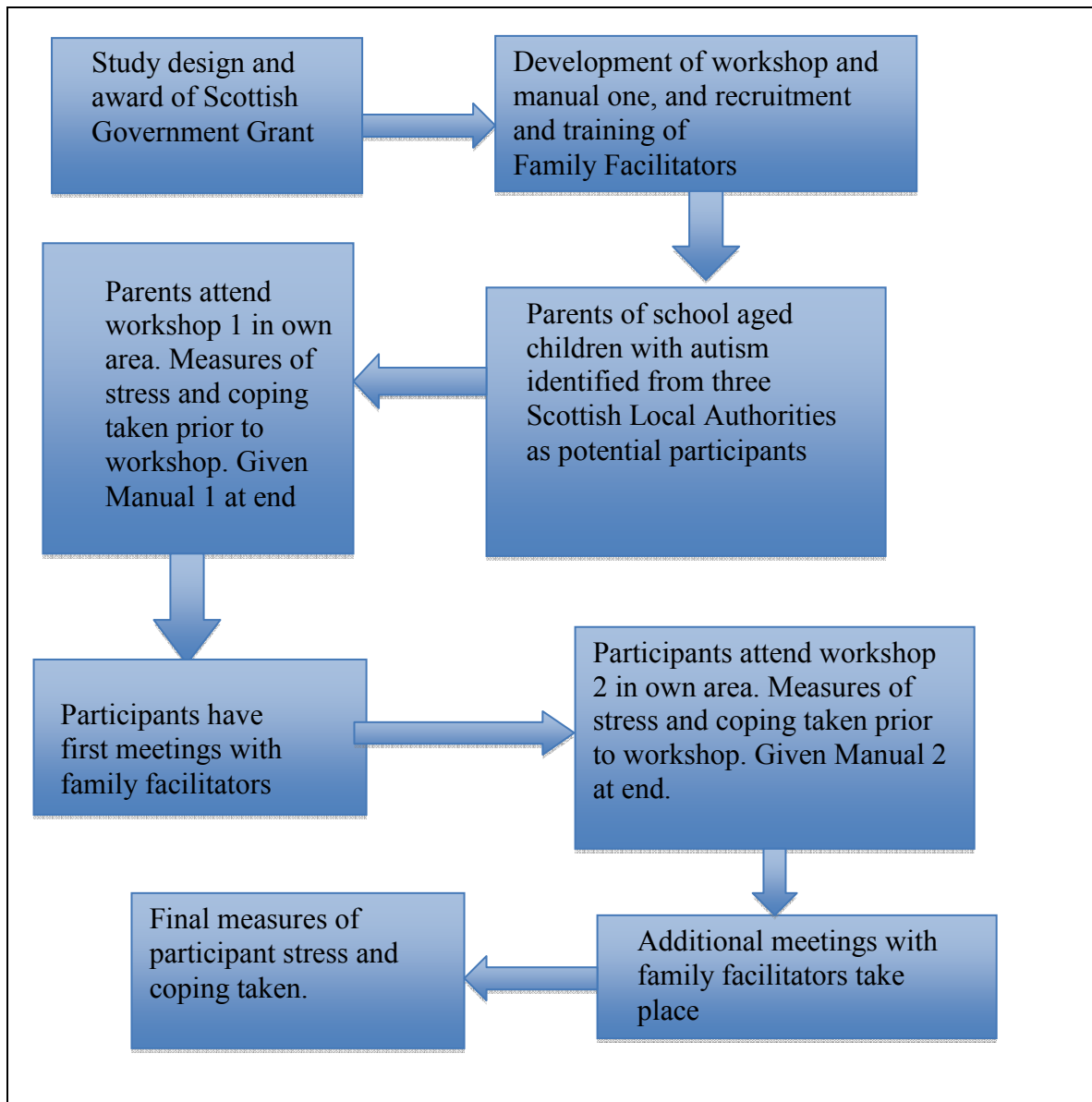


Figure 1. Overall Chronology of Study

1.2.1 Study Aims

Parent mediated interventions for children with autism generally focus on training parents to implement a prescribed programme to alter their child's behaviour and/or teach the child a new skill. Parents participating in such interventions are required to adopt the role of therapist regardless of what new burdens this places on them. However, studies that have evaluated such interventions have identified a

range of methodological issues, raising questions as to their ability to make meaningful change in families of children with autism.

By contrast an approach, which is predominantly psycho-educational aims to equip parents with an understanding of the meaning behind their child's behaviour. Psycho-education refers to the education given to people who are living with emotional disturbances (Rouget and Aubrey, 2007). Psycho-educational interventions promote a humanistic approach to changing behavioural patterns, values, interpretation of events, and the life outlook of such individuals. The rationale behind a psycho-educational approach is that with self-knowledge of own strengths, community resources, and coping skills, the individual is better equipped to deal with the problem and to contribute to his or her own emotional well-being. As an approach, psycho-education can trace its roots to philanthropists such as Johann Heinrich Pestalozzi and Samuel Gridley Howe who used educative methods for providing therapeutic service and care to physically and psychologically compromised people. A more comprehensive discussion of this approach will be provided in chapter 5.

Unlike prescriptive interventions, which teach parents to deliver a "treatment programme" to their child, this intervention exclusively focuses on parental interpretation of their child's behaviour and the meaning derived from this. While many parent-mediated interventions are concerned with measuring change in child behaviour, this study deliberately avoided such objective measures concerning itself exclusively with parental experience of stress associated with caring for a child with autism. This is a significant point, as those involved in implementing the intervention only met any of the children with autism by chance when visiting the family home to meet with the parents participating in the study, rather than by intention.

In common with psycho-educational approaches adopted in studies of schizophrenia, the approach evaluated within this thesis recognised the importance in developing parental understanding of the underlying cognitive differences experienced by their child. To date theories that autism arises out of impairment in cognition associated with either, theory of mind, executive function, or central coherence have dominated much of the literature (Baron-Cohen, 2004). However,

there are other valuable developmental theories of autism that were omitted from the approach due to the limited availability of resource. For example, the developmental studies of Marian Sigman and her colleagues (Sigman and Ungerer, 1984; Ungerer and Sigman, 1981) highlighted that of the multiple areas of sensorimotor development that Piaget delineated, children with autism showed syndrome-specific impairments in only two: imitation and play. Moreover, Pennington and Ozonoff (1991) assert that more than any other neuropsychological area of impairment in autism, imitation appears to meet the four criteria for a primary psychological deficit in autism: universality, specificity, precedence, and persistence. Therefore, while the psycho educational approach described in this thesis acknowledges the importance of other developmental theories in helping parents understand and relate to their child, the time limitations placed on the number of sessions with parents restricted the approach from extending beyond an understanding of the most prolific theories of cognitive difference.

While the approach adopted aims to reduce stress in parents it also recognises the value of coping and observes changes in coping styles used by parents as they interact with the intervention. Coping is considered to be a cognitive process, however, it is problematic in that cognitive coping and cognitive appraisal can be confounded. Appraising a situation, as a threat, may trigger coping, i.e., further thoughts that imply a reappraisal of the same situation as being more or less threatening. In such cases it is difficult to make a distinction between appraisal and coping. Moreover, other conceptual problems arise when coping is to be separated from coping resources (e.g., hardiness, dispositional optimism, self-efficacy, sense of coherence, social support, etc.). Resources can be personal, social or other antecedents of appraisals and coping. While in reality coping resources and actual coping may be difficult to disentangle, it is important to make this distinction in theory and research. Resources are relatively static, whereas coping is a process that depends on these resources. This study utilises the theoretical framework of Folkman and Lazarus (1980) as it recognises coping as a dynamic process. However, there are other theoretical frameworks such as that by Billings and Moos (1981) which groups items within a measure according to method and function of coping. While it would be helpful to discuss the merits of the different approaches to coping and the

unresolved issues of measurement, it is the concept of appraisal (Lazarus, 1991) and its role in the stressful encounter which makes it most attractive for investigating parental stress relative to understanding the child's behaviour.

1.3 Thesis Overview

Chapter 1 The current chapter offers a backdrop to the study as well as providing an introduction to the key variables being explored. The chapter offers an initial rationale, for the approach taken in the intervention design and identifies the hypotheses the study aims to address.

Chapter 2 Provides a review of the literature relating to autism and describes the disability in terms of symptomology and the nature of behaviours exhibited by individuals on the autism spectrum. The chapter also highlights the impact that the behaviours exhibited by children with autism has on families paying particular attention to the sources of stress experienced by parents.

Chapter 3 Discusses the role of coping in parents of children with autism. The chapter explores the transactional model of stress and coping. The chapter makes detailed discussion of the role of appraisal and examines how the model may influence the development of intervention for families of children with autism.

Chapter 4 Provides an overview of common parent-mediated interventions for children with autism. The chapter discusses both the merits and limitations of interventions and examines the gaps in the evidence base.

Chapter 5 Discusses the value of parent mediated interventions and what alternative theories may be incorporated into their design. The chapter discusses how Positive

Behaviour Programming and Motivational Interviewing may offer a more realistic option as components of parent mediated intervention.

Chapter 6 Describes the method employed in conducting the study. The chapter describes the development and content of the intervention, participant recruitment, procedures, measures, and data analyses used in the study.

Chapter 7 Presents the findings from the study. Data analysis methods are described and the results are presented.

Chapter 8 Consists of discussion and conclusion sections for the study. The chapter includes a discussion and interpretation of findings of the research and highlights the clinical implications, limitations of the study, and future research directions.

References contain a reference list of all the citations in this study.

Appendix section includes attachments of relevant documents highlighted in the thesis.

Chapter Two

Autism

2.1 Autism

There is general agreement across the literature that autism is characterised by behavioural patterns that demonstrate some form of qualitative social impairment observed from the very early stages of development (Wing and Potter, 2002). Such patterns of behaviour can be both complex and challenging and are generally viewed as either a result of the biological basis of the disorder (Gillberg and Coleman, 2000) or as a stress response to environmental triggers (O’Neil and Jones, 1997). Moreover, given that at a clinical level autism has been described as a social impairment (Shah, 1986), parents and primary carers of individuals are frequently confronted with bewildering, challenging and paradoxical behaviour which do not meet the expectations of societal behavioural norms (Reese, Richman, Belmont and Morse, 2005).

There is significant debate as to the primary cognitive impairments in autism, with the literature generally being divided into two camps. The first advocating that autism arises out of a form of *mind blindness* or problems *mentalising* (the ability to understand that others have a mental life different from our own) (Baron-Cohen, 1995), within this model it is thought that the behaviours observed in children with autism evolve from an impaired “empathising” system. The term empathising encompasses a range of other terms: “theory of mind”, “mind reading”, “empathy”, and taking the “intentional stance” (Dennett, 1987). As a construct empathy involves two major elements: (1) the ability to attribute mental states to oneself and others, as a natural way to make sense of agents, and (2) having an emotional reaction that is appropriate to the other person’s mental state (Baron-Cohen, 1994). Proponents of this theoretical model propose that many of the challenging and complex behaviours exhibited by children with autism arise from this primary impairment in *mentalising*. In contrast, other researchers propose that impairment in *mentalising* is secondary to a primary impairment in executive processes (Russell, 1997). The *executive dysfunction* theory of autism does not deny the existence of impaired mentalising ability in people with autism, but rather

contends that this arises out of differences in attention, working memory, planning behaviour and regulating and inhibiting impulse control. Proponents of the *executive dysfunction* theory advocate that early social- communication disturbance in autism are exemplified by a robust developmental failure in joint attention (Mundy and Sigman, 1989). Joint attention skills refer to the capacity of individuals to coordinate attention with a social partner in relation to some object or event.

While both the *mentalising* and *executive dysfunction* theories of autism have different aetiological explanations for the observed behaviours, both agree that the cognitive impairment experienced by individuals across the spectrum gives rise to differences in the interpretation and experience of sensory/perceptual information (Hirstein, Iversen and Ramachandran, 2001; Townsend, Courchesne, and Egaas, 1996). Moreover, since the earliest descriptions there has been a general consensus in the literature that people with autism have different perceptual experiences (Kanner, 1943) and that the fluid unification of objects, action and context experienced in typically developing individuals is not as coherent for adults and children on the autism spectrum (Tsermentseli, O'Brien, and Spencer, 2008).

In typical development the organisation and experience of sensory information is central to how we respond to our environment and to our regulation of emotion and behaviour. The ability to selectively attend to identified stimuli and integrate multiple sources of sensory input informs our perception of the world around us and helps us develop a coherent picture of events. Under normal circumstances, multisensory stimulation leads to enhanced perception and facilitated responses to objects in our environment (Bolognini, Frassinetti, Serino, and Ladavas, 2005; Stein, London, Wilkinson, and Price, 1996; Sumby and Pollack, 1954). As such, there exists a plethora of multisensory interactions in the processing of stimulus location, identity, and timing (Calvert, Brammer, and Iversen, 1998; Calvert and Lewis, 2004).

The autobiographical accounts of people with autism, suggests that the subjective sensory-perceptual experiences they have are often different from typically developing individuals. Generally, reports refer to difficulties in the reception (input) and processing (making sense) of sensory information (Cesaroni and Garber, 1991). Personal accounts include examples from vision, sound, taste,

smell, proprioception, kinesthetic stimulation of sensory distortions, sensory tune-out, synesthesia (e.g., a sound provoking sensations of colour or smell), difficulties processing information from more than one modality concurrently, and difficulties identifying the source modality of sensory input (Attwood, 1998; Grandin, 1988, 2000; Williams, 1996).

Children with autism process sensory information in a way that seems to differ from others (Brock, Brown, and Boucher, 2002; Frith, 1989; Happe', 2005; Hermelin and O'Connor, 1970; Hutt, Hutt, Lee, and Ounsted, 1964; Just, Cherkassky, and Keller, 2004; Mottron, Dawson, Soulieres, Hubert, and Burack, 2005). Moreover, they are more likely to present as having unusually intense attention to or avoidance of sensory stimuli from all the modalities (Grandin, 1992; Cesaroni and Garber, 1991; O'Neill and Jones, 1997; Williams, 1994). Atypical responses of individuals with autism are also in part a function of hypo and/or hyper-arousal (Hutt et al., 1964) and unusual reactions to sensory input (Kootz, Marinelli, and Cohen, 1982; Ornitz, 1974; Ornitz, Guthrie, and Farley, 1977). In addition, there is a significant body of evidence to suggest that individuals with autism experience atypical attentional, physiological, and neurological responses to sensory tasks (Hermelin and O'Connor, 1970; Hutt et al., 1964; Ornitz, 1974). The evidence from both personal accounts and empirical studies suggests that sensory atypicalities are core symptoms in children with autism (Happe', 2005; Mottron and Burack, 2001; Just et al., 2004), and that many of the disruptive behaviours we observe are in part a result of these sensory experiences. Findings from studies that have explored the role of poor sensory integration in challenging behaviour indicate that parents are often confronted with behaviour which is not only challenging but as in the case of self injurious behaviour arising from poor integration, potentially dangerous (McIntosh, Miller, Shyu and Hager, 1999). However, few if any parent-mediated interventions take consideration of the phenomenological difference experienced by children with autism of day-to-day sensory inputs and their resulting impact on behaviour.

Whilst, behaviours presented by those on the autistic spectrum can be found within the general population and within individuals who experience other disorders and disabilities, it is the severity and frequency of specific enduring patterns of

behaviour that is indicative of autism spectrum disorders (Posserud, Lundervold and Gillberg, 2006). In addition to self injurious behaviour arising from poor sensory integration individuals can present with: violent behaviour, inappropriate sexualised behaviour, tantrum, problems with communication, property destruction, difficulties in relating to others, making inappropriate verbal comments, difficulties with sharing space, turn taking, problems with impulse control and strange and awkward body movements (Mc Clintock, Hall, and Oliver 2003; Baghdadli, Pascal, Grisi and Aussilloux, 2003; Chadwick, 2000). Such behaviours, while being socially inappropriate also cause extreme distress not only to the individual who is presenting them, but also to parents, siblings and professionals involved in the child's care and education.

The lack in understanding of social norms and cues central to autism has significant impact on how that individual relates to others and can place significant strain upon relationships (Wing and Gould, 1979). In addition, given that 10-20% of children with autism and learning disability exhibit behaviour such as self-harm and aggression with a likelihood of severity increasing into adolescence (Jacobson 1982; Kiernan and Kiernan 1994), the quality and type of interactions which parents have with their child may be significantly restricted and contingent on the parents ability to cope with the demands placed on them.

2.2 Parental Stress

2.2.1 *Systemic Issues*

The sources of stress on parents are varied and multiple, and include having to relate and interact with statutory and support agencies, deal with economic pressures, maintain the welfare of siblings, manage concerning behaviours presented by their child with autism, ensure the safety for their child with autism, as well as the day-to-day hassles of ordinary life (McCubbin, Cauble, and Patterson 1982). In addition to the unique pressures related to the nature of the disability itself (Hastings *et al.*, 2005), parents of children with autism are confronted with the same systemic issues as parents of children with other disabilities.

For many parents having a child with a disability will bring them into contact with statutory agencies for the first time. This can place new and additional demands on them as they attempt to navigate through unfamiliar systems and language leaving them bemused as to how to access support or what they can expect from different local authority or government agencies (Alderson and Goodey, 1999). Furthermore, the burden of care may require parents to consider their ability to remain in full time employment. In their study of mothers of children with disability, Curran, Sharples, White, and Knapp (2001) estimated that following the birth of the child, 67% of mothers are unable to maintain paid employment, placing additional economic pressures on the family and potentially leading to mothers feeling more isolated. This is a significant point when considering the mental and physical health of parents of children with autism. The withdrawal of parents from full or part time employment not only places financial strain on the family, but it also restricts opportunities for caregivers to develop their own social relationships and contributes to the development of emotional exhaustion by cutting off networks that may offer social support (Hauser-Cram, Warfield, Shonkoff and Krauss, 2001; Hastings and Brown 2002).

2.2.2 Parental Stress, Behaviour and Sibling Relationships

The behaviours exhibited by children with autism not only place demands on their parents, but inevitably also places considerable strain on sibling relationships (Sanders and Morgan, 1997). Children with autism are more likely to have a restricted repertoire of play, poor eye contact and experience difficulties with joint attention which not only limits social responsiveness but can create further disruption to family life by impacting upon the quality of interaction with other children within the family (Harris, 1994; Knott, Lewis, and Williams, 1995; Sanders and Morgan, 1997). Furthermore, studies have suggested that siblings of children with autism can experience fear or be disturbed by their sibling's challenging and bizarre behaviour (Bägenholm and Gillberg, 1991; Roeyers and Mycke, 1995). While studies examining the quality of relationships between siblings where one has autism has drawn conflicting conclusions (Fisman Wolf, Ellison, Gillis, Freeman, and Szatmari, 1996; Kaminsky and Dewey, 2001; McHale, Sloan, and Simeonsson, 1986), there is

general acknowledgement that parental stress is influenced by concern over the quality of interaction between siblings and anxiety over issues of welfare and safety for non disabled siblings (Sherman 1988; Rousey, Blacher and Hanneman, 1990; Bromley and Blacher 1991; Kobe Rojahn, and Schroeder, 1991; Stoneman and Berman 1993).

Where parents are unable to manage the behaviour presented by their child with autism and/or where there is considerable concern for the welfare of a sibling, parents and statutory services may have to consider alternative accommodation such as a specialist residential school. This has both direct and in-direct consequences for parental stress. Kiernan and Kiernan (1994) estimated that about 35 children within each local authority area move from local severe learning difficulties (SLD) special schools to residential provision each year in England and Wales because of problem behaviour. In addition to feelings of guilt and loss experienced by all family members, the distance between the family home and a residential school has the potential to place additional stress and impact on relationships within families through its impact on the maintenance of family contact (McGill, Tennyson, and Cooper, 2006). In a study by Abbot, Morris and Ward (2001), that surveyed all disabled children attending residential schools in England and Wales, severe learning difficulties and autism were the most frequent categories of primary special educational need.

The concern for the welfare of non-disabled siblings relates to the most significant predictors of parental stress namely: behaviour, age and size (Tausig 1985; Sherman 1988; Rousey *et al.*, 1990; Bromley and Blacher 1991; Kobe, Rojahn, and Schroeder, 1991; Blacher, Hanneman, and Rousey, 1992). In their longitudinal study of 3-year olds with and without disabilities, which included children with autism, Baker, Blacher, Crnic and Edlebrock (2002) reported that when the influence of behaviour problems on parenting stress was accounted for, mental development explained no additional variance. Hastings, *et al.* (2005) observed that families and carers report significant stress in managing and responding to behaviour that is perceived as being anti-social. As discussed above the behavioural characteristics associated with autism are not only those aspects of behaviour which are difficult to manage but also those aspects which do not seem to fit into

behavioural patterns that are typically expressed in most social context. While different cultures may have subtle differences in what is generally thought of as socially acceptable behaviour, it remains that many of the behavioural features associated with autism appear at odds with most cultural expectations of child behaviour.

Chapter Three

Coping

3.1 Life Satisfaction in Parents

In their study of life satisfaction in parents of children with autism, Milgram and Atzil (1988) found that parents did not relate life satisfaction to objective evaluations of their child's behaviour (as rated by teachers, principals and psychologists), but rather to their ratings of their own parenting behaviours, such as level of parenting difficulty, proportion of parenting tasks and fairness. This suggests that while child behaviour may be a significant predictor of stress in parents, it is how the parent perceives their own role and behaviours that influences their own satisfaction

Scorgie and Sobsey (2000) label three transformational outcomes associated with parenting a child with a disability; *personal transformations* in relation to the acquisition of roles or traits, *relational transformations* with regard to family relationships, advocacy relationships, friendship networks and attitudes towards people in general, and *perspectival transformations*, which concern changes in how people view life. Within this paradigm no value is placed on the nature of the transformation, it is neither ascribed as being positive or negative.

In their study of mothers of children with autism, Tunali and Power (1993) found in a sample of 29 mothers that those who showed the greatest life satisfaction appeared to be those who were able to redefine those elements of their experiences that would provide fulfilment and in the process redefine what provides fulfilment. This has echoes of Scorgie and Sobsey's transformational construct. As with the construct of transformation, Tunali and Power conclude that where mothers are able to re-appraise their lives, such as moving from being career orientated to family orientated and where they perceive readily available support from their partners and/or family, they are likely to experience less distress.

3.2 The Transactional Model of Stress and Coping

Our beliefs regarding our roles within our interactions provide meaning to experience, as well as offering a basis for appraising and integrating those experiences (Damasio, 2000). The ability to frame ourselves and our experiences, is significantly influenced by the beliefs we hold and how they shape our sense of identity. Beliefs, whether they be implicit or explicit have been shown to shape established ways of responding to events and people, as well as our ability to cope with stressful situations (Lazarus and Folkman, 1984). This suggests a role for conscious strategies in responding to stressful events (Billings and Moos, 1981; Folkman, 1984), as deriving meaning from a stressful situation can influence our response to it.

Variables associated with coping have been identified as providing a possible moderator effect in the relationship between stressful events and psychological and somatic symptoms (Endler and Parker, 1988; Folkman, Lazarus, Gruen and De Longis, 1986). The suggestion of such studies is that coping is an interactional process, where well-being is influenced by the interaction between coping strategies (variables which are person oriented), and stress generated by the situation/ event (situational variables), (Taylor, 1991).

3.2.1 The Role of Coping

Coping would seem to play two important functions: regulating stressful emotions (emotion-focused coping) and altering the troubled person-environment relation causing the distress (problem-focused coping), (Andrews, Pollock and Stewart, 1989; Folkman and Lazarus, 1985; Miller, 1987). A number of studies in this area place emphasis on the identification of individual coping styles and discussion has focussed around the features and dimensions associated with coping responses (Endler and Parker, 1990; Folkman and Lazarus 1980). However, a consensus generally remains among studies which have explored stress and coping from an *interactional* paradigm, that there are two dimensions of coping response *Problem focussed or task- oriented coping* and *emotion -oriented coping* (Miller, 1987; Endler and Parker, 1990; Folkman and Lazarus, 1985).

3.2.2 The Role of Appraisal

The theory of psychological stress outlined by Folkman *et al.* (1986) identifies cognitive appraisals as critical to the stressful person-environment relations and their immediate and longer term outcomes. *Cognitive appraisal* is a process through which an individual evaluates whether a particular encounter is relevant to his or her well-being, and if so, in what ways. This construct can then be further divided into primary and secondary appraisals. A *primary appraisal*, is that which involves an evaluation by the individual as to whether there is a cost or benefit to their well being in this encounter. For example, is there a potential harm or benefit with respect to commitments, values, or goals? Is the well-being of a significant other such as a child at risk? Is there the potential for harm or a benefit to self-esteem? Such appraisals' are made on a day-to-day basis by parents of children with autism.

A *secondary appraisal*, requires the individual to evaluate what if anything can be done to avoid or prevent harm or to improve the prospects for benefit. Here a number of coping options are considered, such as altering the situation in some way, accepting the situation, attempting to gain more information, or holding back from acting impulsively which could in turn have some form of cost to the individual, particularly if they perceive the situation to be in crisis. *Primary* and *secondary* appraisals converge in determining if the interaction between the individual and the environment is in some way relevant or significant for well-being, and if so, whether the encounter is primarily threatening with potentially negative outcomes, or challenge which may result in mastery of the situation and ultimately positive outcomes, figure 2 on p.27 illustrates the sequence of *primary* and *secondary* appraisal.

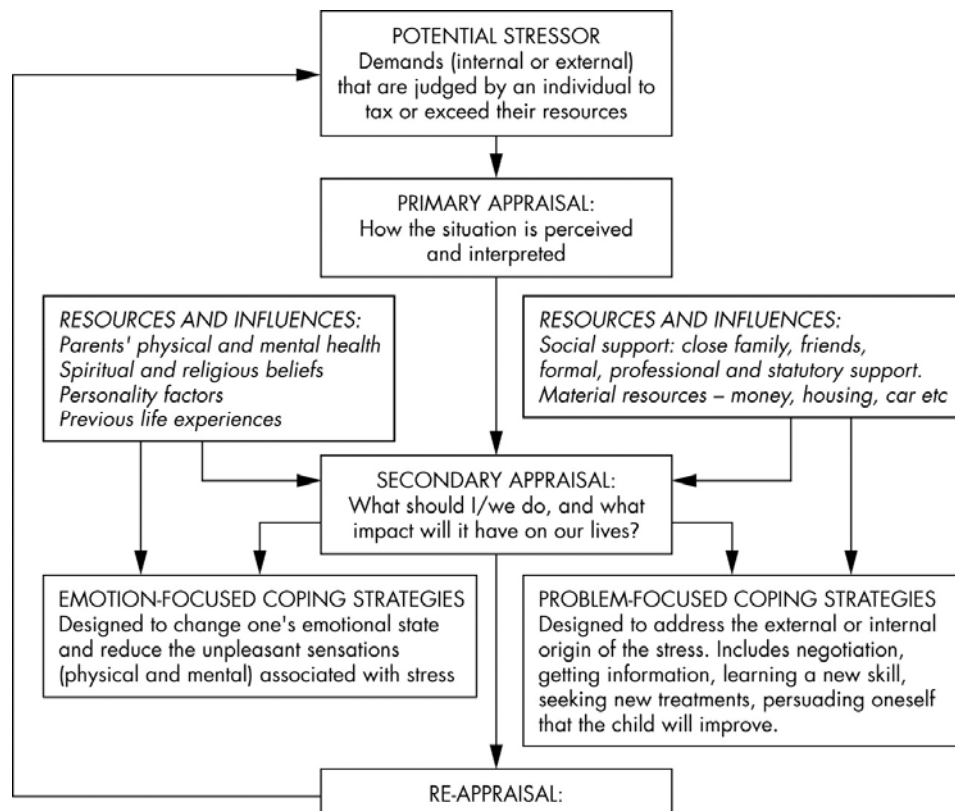


Figure 2, The Transactional Model of Stress and Coping (Lazarus and Folkman (1984)

3.2.3 Coping and Appraisal within Dynamic Context

Within the model outlined above *coping* is defined as the individual's dynamic process of adapting cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as placing stress on an individual's resources (Lazarus and Folkman, 1984). This definition incorporates three principal characteristics. Firstly, it is *process oriented*, focussing on what the individual thinks and does in a given stressful encounter, and how this dynamic alters as the encounter progresses. Secondly, it is viewed as *contextual*, being influenced by the individual's appraisal of the demands (made of the individual) within the encounter and resources required for managing them. This emphasis on context implies that the combination of person and situation variables together influence the outcome of coping efforts. Thirdly, the definition postulated by Folkman and Lazarus (1980) makes no assumption as to what constitutes good or bad coping.

Simply put, coping is an individual's efforts to manage demands, irrespective of whether they are successful.

As will be discussed in the following chapters, many parent-mediated interventions for children with autism take little if any consideration of the dynamic process involved in managing the child's behaviour. The dynamic nature of stressful encounters experienced by parents requires intervention to consider parental appraisal styles and explore the personal resources available to the parent within the given context.

3.2.4 Controllability

Folkman and Lazarus (1980) found that individuals are more likely to employ task or problem-focused coping styles when they appraise a situation as changeable, and more likely to employ *emotion-focused strategies* when they appraise a situation as unchangeable. If an individual considers that they are unable to place any control on the situation, individuals are more likely to use *emotion-focused coping* as described above. However, if the individual perceives that they are able to have some element of control over the situation then they are more likely to employ *task-oriented coping* strategies.

Parents of children with autism are continually exposed to stressful events that have elements of both low and high controllability. The degree of controllability can be influenced by a number of factors such as environment, child mood, social support, child frustration and parental exhaustion. Given that perceived controllability will vary within each situation, it seems plausible that intervention for parents should assist them in assessing those aspects of their child's behaviour where an *emotion focussed coping style* such as allowing the child to calm is best employed and those where a *problem or task-oriented coping style* such as using behavioural strategies is best employed.

Furthermore, a number of studies have examined the qualitative nature of the primary appraisal and its' impact on coping, (Lazarus and Smith, 1988; Smith, Hayes, Lazarus and Pope, 1993; Smith and Lazarus, 1993). These studies describe a conceptually similar, if not identical, component of primary appraisal termed *motivational relevance*. *Motivational relevance* can be viewed as an evaluation of

the extent to which the encounter touches on personal commitments, goals, and concerns, such as ensuring child welfare and maintaining family relationships. In a college student sample, Smith *et al.* (1993) found that greater motivational relevance was related to stronger emotional responses to stressors, demonstrating that those events viewed by the individual as being highly significant will result in more stress. We would therefore consider that many encounters experienced by parents of children with autism will have *motivational relevance* and it is possibly this factor that plays a significant role in determining the coping styles adopted by individual parents. However, it is possibly the interaction between the primary appraisal and the degree of controllability perceived when making secondary appraisals that predicts parental distress.

3.2.5 Adapting Coping Style

On reviewing the *transactional model of coping* Scale, Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) found that individuals were more likely to use both *confrontive coping* (a task oriented coping style) and *self control* (an emotion focussed coping style) in encounters where they viewed there was the risk of loss of respect for another. This would be the case for a parent of a child with autism where onlookers within a public setting consider the child's behaviour as inappropriate. Similar to earlier findings *Accepting responsibility* (task oriented) and *positive reappraisal* (emotion focussed) were found to be employed by individuals where the encounter was viewed as being changeable. This finding is consistent with other studies, which found that positive reappraisal facilitates *task- oriented coping* (Aldwin and Revenson, 1987). In addition, (Folkman *et al.*, 1986) found that where individuals viewed situations that were changeable they used coping styles that enabled the individual to focus on the situation they confronted, did *playful problem-solving*, *accepted responsibility*, and selectively attended to the positive aspects of the encounter. It would therefore seem that an individuals ability to adapt coping style relative to how they perceive they can exert influence on a stressful situation will in part determine the physical and psychological impact of the stressful encounter. However, as acknowledged by the authors there are limitations to understanding causal direction, particularly in understanding the role of appraisal.

While appraisal may influence coping, it is also possible that coping may influence the person's reappraisal of what is at stake, and what coping options exist. This has a "knock on" effect for intervention as it would seem important that in addressing stressful situations, parents experience success through their ability to adapt their coping style as the stressful situation unfolds. If intervention is able to assist parents of children with autism in identifying those aspects of the child's behaviour that they feel they have the coping resources to address and experience some success in, it is possible that parents will re-appraise the challenging nature of that behaviour. Moreover if an individual experiences a reduction in distress from using a *problem-solving approach*, and perceives that the situation is changeable, then they are more likely to use this approach in the future. However, if an individual experiences an increase in distress they are more likely to reappraise the situation and view it as less changeable. The implication being, that for parents of children with autism we should consider focussing on those situations that are more likely to provide positive re-appraisal, and combine this with psycho-educational approaches that encourage *problem-solving* strategies for specific behaviours.

3.2.6 Parental Appraisal and Understanding the Child's Autism

In addition to a parent's perception of triggers and setting events, parental affect during stressful encounters with their children is influenced by a variety of both child and parent characteristics and the degree to which they interact. Lazarus (1991) suggests that causal attributions are forms of knowledge rather than appraisals since they do not have similar emotional implications for all individuals under all circumstances. This *Cognitive-motivational-relational* theory contends that appraisal rather than attributions provide the link to emotional experience. In situations where an individual holds an understanding of the locus of causality of a stressful event either to the self or to an agent outside of the self, (such as relating the event to a child's disability), then we would anticipate that the individual will experience a range of emotions as part of the process of appraisal. The nature and degree of emotion experienced is dependent on the meaning of the event to the individual. Meanings can either be congruent or incongruent depending upon whether the individual assigns credit or blame when determining causality within the event.

While credit can take the form of pride, positive affirmation of self image or improved self efficacy, blame can be directed as anger to an external agent or as guilt, when directed inwardly. This may in part explain observations of parental behaviour as a response to an on-going chronic stressful situation. In their study of American Latino mothers of children with autism, Chavira, Lopez, Blacher, and Shapiro (2000) found that mothers who attributed a high versus low degree of responsibility to their children when they exhibited problem behaviours were significantly more likely to report experiencing negative emotions such as anger or frustration and to report that they typically respond in aggressive or harsh ways. Moreover, studies which have examined self blame in mothers of children with developmental disorders such as autism, have found that the experiences of grief, shock, confusion, fear, worry, isolation, anger, numbness and sadness, when given a diagnosis can often be combined with cognitions of questioning if they somehow inadvertently contributed to their child's atypical developmental pattern (Siegel, 1997; Sullivan, 1997). The above suggests a fairly important role for parental understanding of autism and how it presents in their child. Parental appraisal of child behaviour and the parents' ability to relate that to the child's autism or stage of development has significant implications for how that parent copes with on-going care demands.

In Lazarus' theory the knowledge an individual holds regarding locus of causality is insufficient to develop affect. It is when this knowledge is used to appraise the relevance of the event to the individual's goals, and whether it is congruent or incongruent with those goals that determines emotional outcomes such as self-efficacy, blame or anger. For parents of children with autism the child's disability, the resulting atypical behaviour and the level of social stigma combine to influence emotional outcomes as both an on going process and as events are played out on a day-to-day basis. The role of intervention should then be to assist parents of children with autism to develop knowledge and understanding of their child's behaviour. This can assist parents in establishing realistic expectations of their child rather than have unrealistic goals of child behaviour that may cause distress in both child and parent.

A number of studies have highlighted the use of reframing strategies to allow individuals to cope with low control situations and thus reduce the impact of stress (Folkman *et al.*, 1986; Rothbaum, Weisz, and Snyder, 1982). How an individual appraises a stressful experience at both a primary and secondary level has significant implications for which coping strategies they will employ both now and in the future. However, there remains a significant gap in our understanding as to how problem-appraisal strategies fit into situations where there is an on going process of coping with an uncontrollable, long-term stressor such as caring for a child with autism. Using Maslow's hierarchy of needs (Maslow, 1954), Tunali and Power (1993) examined some of these issues in parents of children with autism. In their analysis, the authors concluded that where individuals perceive that basic human needs are under threat, they are likely to redefine what constitutes fulfilment of those needs and seek alternative ways of meeting them. Using the same methodology Tunali and Power (2002), examined role definition in 29 mothers of children with autism, matched against 29 mothers of children who were typical in development. Hypotheses tested included views such as: mothers of children with autism would place greater emphasis on child rearing than career development, and mothers of children with autism would place greater emphasis on family leisure time than a mother of the typically developing group. While the study showed that mothers of children with and without autism did not differ overall in psychological adjustment, life satisfaction, or marital satisfaction, mothers of children with autism who showed the greatest life satisfaction appeared to be those who made redefinitions. In addition, the study found that mothers of children with autism placed less emphasis on the opinion of others regarding their child's behaviour, than did mothers of children without autism.

3.2.7 Centrality

In some instances, stressful events may be perceived by an individual as central to their well-being, as the stakes involved are particularly high. Such instances may be where the stressful event involves the safety or welfare of a significant other and where a strong bond or attachment is involved. This notion of *centrality* as a component of a primary appraisal has been hypothesised as an

important mediator in stress (Lazarus and Smith, 1988; Smith *et al.*, 1993), particularly as individuals are more likely to use *emotion-focused* strategies during such encounters. A number of studies have shown a positive relationship between caregiver stress and specific behaviours such as physical aggression, self-injurious behaviour and restlessness, which are frequently exhibited by individuals with autism (Konstantareas and Homatidis 1989; Freeman, Perry and Factor, 1991). During episodes of challenging behaviour, the stakes to the caregiver may be significantly high, particularly where the event may be witnessed by bystanders or where there is a risk of harm to either child, parent or a third party. Moreover, such situations may be perceived by the parent or caregiver as *low control* situations. As described earlier *Low control* situations are characterised by context where the individual may hold the belief that there is little or nothing that can be done to influence the nature or the outcome of the situation (Folkman, 1984; Roth and Cohen, 1986). The literature within this area is somewhat equivocal. Researchers such as Roth and Cohen (1986) and Wortman and Brehm (1975), suggest that the use of problem-focussed coping in low control situations is likely to have a detrimental effect, due to the frustration and disappointment experienced by individuals as a result of being unable to effect change on the situation. Likewise, Masel, Terry, and Gribble (1996) propose that emotion-focused coping responses are adaptive, and due to the need to deal with the feelings of hopelessness that are typically generated by low-control stressors, may offer a more appropriate coping style. However, this *goodness of fit* model, where coping styles are employed relative to adaptation and levels of control within the situation, has been found to be inconsistent across a number of studies (Felton, Hinrichsen and Revenson, 1984; Forsythe and Compas, 1987).

3.2.8 Goodness-of-Fit

The lack of consensus regarding the relationship between coping style and perceived controllability of an event is reflected in Vitaliano, DeWolfe, Maiuro, Russo, and Katon's (1990), study of people with psychiatric, physical health, work, and family problems (n = 746). When examining correlations between problem-focussed coping and stress related symptoms such as depression in low control

situations, the authors did not find any relationship as suggested within the goodness-of-fit model. Moreover, in perceived unchangeable situations, the study did not find any relationship between emotion focussed coping and positive adjustment. Counter to the goodness-of-fit model all three groups showed a positive relationship between emotion-focussed coping and depression, although this was only statistically significant in one sample. The Vitaliano (1990) study was replicated by Conway and Terry (1992) with similar findings, supporting the notion that predicting coping style relative to perceived control of event, remains contentious. However, Terry and Hynes (1998) have sought to resolve inconsistencies within the *goodness-of-fit* model by re-conceptualising the construct of problem-focussed strategies. They contend that problem-focussed approaches can be sub-divided into two forms: problem management strategies and problem appraisal strategies. *Problem-management* strategies are efforts to address the problem through developing plans of action they are solution focused in nature and focus the individual's resources on finding a solution. While *Problem-appraisal* strategies are also directed towards the management of the problem, they do not directly address the content and detail of the stressful event. Instead they are employed by the individual to assist in the appraisal and assessment of the event. Positive reframing and seeking opportunities for development from the event are all cognitions associated with problem appraisal strategies. Likewise the authors propose that emotion-focussed coping can be subdivided into *avoidant-coping*, associated with wishful thinking, escapism and disengagement and *emotional approach* coping associated with, expression of emotion pertinent to the stressful situation. In developing parent mediated interventions in families of children with autism, it would seem sensible to consider how parents frame events particularly when it comes to their understanding of their child's behaviour. As suggested there may be scope for growth and development within parents who learn the context in which problem appraisal strategies are the most effective.

3.3 Coping within the Context of the Family

World views are the family's assumptions about the social and cultural environment, and their family's place in the world (Patterson, 1991). Belief systems constitute the core of a family's overall resilience (Hawley and DeHaan 1996; Walsh 1998). They provide anchorage and stability, and a shared sense of meaning that helps families pull together and face future challenges (McCubbin and McCubbin 1993). Belief systems also serve as cognitive maps that guide the choices families make for their everyday activities (Rolland 1993; Kumpfer 1999). Central to this notion of pulling together is the idea of a sense of coherence, which enhances the family's resilience. Rutter (1993) suggested that resilience is dependant on how individuals reframe events and experiences as a means of deriving meaning from their change in circumstances. This ultimately allows the individual to change how they view their place in the world, and while initially viewing their situation as being a negative experience through a process of reframing, individuals are able to adapt their cognitions and view their place in society from a more positive perspective. Studies which have examined families where a child has additional support needs indicate that families that seem to cope are those that can attribute positive meanings, are able to exercise some control over their situation and are able to reframe the family context as manageable (Summers, Behr, and Turnbull, 1989; Patterson 1991; Kazak, McClure, Alderfer, Hwang, Crump, Deatrick, Simms, and Rourke, 2004). Moreover, Samios, Packenham and Sofronoff (2008) found that parents of children with autism who were able to construct benefits relating to their child's disability had a greater sense of cohesion.

Chapter Four

Parent-Mediated Interventions

4.1 Intervention in Autism

In May of 2013 the American Psychiatric Association (APA) will publish the updated Diagnostic Statistical Manual (DSM V) in which a more dimensional approach to diagnosing autism will be described. The continued clarification of the deficits in social interaction and communication while confirming the prevalence and complexity of this disorder also emphasises the gulf between basic science and therapeutic intervention, intensifying the distress and frustration of many parents.

Parents are confronted with an ever increasing and changing number of interventions that purport to improve the symptoms associated with autism. Therapies which have received considerable attention include pharmacological therapies and various complementary therapies such as diet modifications and vitamin therapy as well as therapies offered within the health, social and educational systems which include occupational therapy, speech and language therapy and behavioural and developmental approaches (Volkmar, Paul, Klin and Cohen, 2005). The bewildering assortment of interventions, books, DVD's and general information circulating the internet on how to best intervene with a child who has autism can often leave parents confused and anxious. Some therapies make dramatic and questionable claims such as being able to cure autism (Kaufmann, 1994) with others offering a pseudo-scientific basis derived from other areas of scientific enquiry such as Mercury Chelation Therapy (Bradstreet *et al.*, 2003), or Auditory Integration Therapy (AIT) (Berard, 1983). The frustration felt by parents often leaves them vulnerable to dramatic claims, with many parents feeling the need to take action irrespective of emotional and financial cost (Fitzpatrick, 2008). In 2007 the Shirley foundation carried out an evaluation of the aggregate national costs of supporting school aged children with autism in the U.K. In considering the breadth of the spectrum, the study concluded that the then public expenditure alone was approximately £2.7 billion per annum, with conservative estimates of lifetime costs ranging from £2.9 to £4.7 million per person. Despite the large sums of both public and private money, autism remains a life long condition with no cure (Frith, 1989)

In general, therapeutic interventions for promoting social, adaptive and behavioural function in children with autism that have a more credible evidence base (National Research Council, 2001; Scottish Intercollegiate Guidelines Network, 2007) fall within a continuum of behavioural and developmental interventions. Such interventions range from highly structured therapist guided behavioural approaches to social pragmatic approaches that follow the child's interests and are set within the schedule of daily activities of the school, home or leisure environment. It is from both the behavioural and developmental literature that most parent-mediated interventions are developed (Howlin, Magiati and Charman, 2009; Sofronoff, and Farbotko, 2002).

4.2 Parent-Mediated Intervention

There has been an increasing shift towards involving parents as therapists with a number of interventions delivering training to parents so that they become both parent and therapist. The general rationale for taking this approach has been to increase the availability and intensity of interventions and has been adopted by most therapies that have a focus on behaviour management or skill acquisition (Lovaas, Koegel, Simmons, and Long 1973; Schopler and Mesibov, 1984; Schreibman, Koegel, Mills and Burke 1984; Mahoney et al. 1999). However, research to date has focused almost exclusively on the outcome for the child, and there is little known about the effects of involvement for the whole family or the impact on parents of delivering such interventions. The scope of this thesis is not broad enough to carry out a detailed description and critique of all parent-mediated interventions. Rather this thesis reviews five approaches that cite either developmental or behavioural paradigms as a basis for their approach, are aimed primarily at parents, and are used within the UK (Diggle, and McConachie, 2002; Roberts and Prior, 2006; National Autistic Society, 2007).

4.3 Behavioural Approaches

Therapist guided behavioural approaches derive their theoretical basis from early behaviourist orientated learning theory (Skinner, 1953). Early animal research asserted that an animal's behaviour could be shaped through conditioned reinforcement and that the function of behaviour could be understood from a classical conditioning paradigm (i.e., an initially neutral cue acquires value because of its association with primary reinforcement). This cue value interpretation of behaviour was adapted and researched for the development of skill acquisition in children with autism (Lovaas *et al.*, 1966) and is routinely used in Discrete Trial Training (DTT) (Lovaas *et al.*, 1981) and Pivotal Response Training (Schriebman and Koegel, 2005), the key approaches employed in Applied Behaviour Analysis (ABA) (Cooper, Heron and Heward, 2007).

Green *et al.* (2006) identified 111 treatments used by parents of children with autism with their findings indicating that the most used treatment categories are standard therapies and treatment focusing on skills training, especially those based on the principles of Applied Behaviour Analysis.

4.3.1 Discrete Trial Training

The cornerstone of DTT is the specification and measurement of achievable learning objectives (Smith, 2001), which are then broken down into small teachable steps that are presented in the format of a discrete trial (Cohen, Amerine-Dickens, and Smith, 2006; Eikeseth, Smith, Jahr, and Eldevik, 2002). A particular trial may be practiced numerous times until the skill is mastered.

Smith (2001) identifies three steps that are common to all discrete trial methods:

- The discriminative stimulus (SD) - the instruction or environmental cue of which the therapist expects a child's response (e.g., "What colour is it?", "Point to the ball", or "Do what I am doing!", etc.)

- The child's response - the skill or behaviour that is targeted. If the child does not respond or responds incorrectly, usually the therapist would then provide a prompt to ensure learning.
- The consequence - usually in the form of reinforcement, a reward that is intended to motivate the child to respond in this same way more in the future.

This procedure is repeated until the therapist is confident that the child has mastered the skill. The therapist can then manipulate the discriminative stimulus and consequence in subsequent steps to facilitate the child's attainment of the overall learning objective. Possibly the most evaluated ABA approach which has the principles of DTT at its core is the UCLA Young Autism Project developed by Lovass and colleagues (1981), which has evolved into what is commonly referred to as Lovass therapy (Maurice, Green and Luce, 1996) and which is referred to under a range of other ABA headings (Handleman, Harris, Arnold, Gordon, and Cohen, 2006). Lovass based approaches are performed within either the school or home environment and within a one to one context where the child cannot be easily distracted by other stimuli. This labour intensive requirement has significant implications for classroom management and the availability of home and school resources, particularly at a time of limited public sector finances.

4.3.2 Pivotal Response Training

In contrast to the highly structured therapist led approach of DDT, Pivotal Response Training (PRT) is a loosely structured, naturalistic intervention relying on naturally occurring teaching opportunities and naturally occurring consequences (Schreibman, 2000). Unlike DDT, which provides reinforcement not related to the task, such as offering food for completing a visual matching activity, PRT uses reinforcement directly related to the activity the child is engaged in. For example, if a goal of intervention is to teach the child to wait and take turns, then the therapist may use a naturally occurring play scenario, providing reinforcement by offering a choice of toys favoured by the child for waiting appropriately for their turn in the game.

An overall aim of PRT is the improvement of autonomy, self-learning, and generalisation. Koegel, Koegel, Harroer, and Carter (1999) identify the following four pivotal behaviours: responsivity to multiple cues, motivation, self-management, and child self-initiations, which should be targeted through the procedure outlined below:

Procedural Core Elements of PRT

1. The instruction should be clear, appropriate to the task, uninterrupted, and the child should be attending to the therapist or task
2. Maintenance of previously mastered tasks should be interspersed frequently
3. Multiple cues (such as verbal, gestural, visual) should be presented if appropriate for the child's developmental level
4. The child should be given a significant role in choosing the stimulus items.
5. Rewards should be immediate, contingent, uninterrupted, and effective.
6. Natural or direct reinforcers should be used the majority of the time with rewards being contingent on response attempts.

Both DTT and PRT fall under the umbrella of the general term Applied Behaviour Analysis. While there are a number of variants of ABA, the principles and procedures are generally consistent to those found in DTT and PRT (Cooper Heron, and Heward, 2007; Steege, Mace, Perry and Longnecker, 2007). However, a number of authors have highlighted inconsistencies of the effects of discrete trial learning. Studies that have compared discrete trial training to controls where no treatment was provided, have reported positive statistically significant findings only in motor and functional outcomes. In contrast, speech-related outcomes, were generally negative (Howlin, 1981; Pechous, 2001). Furthermore, while behavioural therapy may be provided for up to 40 hours per week (SIGN, 98) there is still significant debate as to the intensity required to achieve positive outcomes (McEachin, Smith and Lovaas 1993; Howard, Sparkman, Cohen, Green and Stanislaw, 2005). In addition, a meta-analysis by Hourmanesh (2006) suggests a lack of evidence to assert that one approach within the ABA framework is more effective than another.

While proponents of ABA advocate its empirical rigour (Green *et al.*, 2006), others have highlighted that this is overstated pointing out methodological issues regarding treatment integrity (the consistent implementation and delivery of the programme) (Howlin, Magiati and Charman, 2009). Wheeler, Bagget, Fox and Blevins (2006) reviewed a series of behavioural intervention studies of children with autism (n = 60), which had been published across 9 journals specialising in the areas of autism and/or developmental disability between the years 1993–2003. The review established that only 11 studies of those reviewed operationally defined the independent variables and assessed treatment integrity. Similarly, McIntyre, Gresham, Di Gennaro, and Reed (2007) reviewed school- based intervention studies published in the Journal of Applied Behaviour Analysis between the years 1991 and 2005 (n=142). The authors found that only 30% of the studies reviewed provided data regarding treatment integrity. The issue of treatment integrity is an important one. Not only because it limits any assertion by proponents of an approach that there is a relationship between the independent variable and the efficacy of the approach, but it also has significant implications for the teaching of that approach to non-professionals such as parents, whose prior knowledge, experiences, beliefs and relationship to the child will be different from that of the therapist.

A review of guidelines and systematic reviews (Scottish Intercollegiate Guideline Network, 2007; Howlin, Magiati and Charman, 2009; McConachie and Diggle, 2007; *Eldevik et al.*, 2009) suggests that the ABA approaches most commonly employed in parent mediated intensive behavioural programmes are those based on the principles of DTT and PRT. A number of studies (Lord *et al.*, 2005; National Research Council, 2001 and Smith, Donahoe and Davis, 2006) identify early intensive home-based behavioural interventions (EIBI) as being among the most thoroughly evaluated of the ABA approaches.

4.3.3 Problems with ABA Approaches

Fundamental to ABA is the principle of objective measurement and the use of empirically driven analysis (Baer, Wolf and Risley, 1987). In keeping with these principles, most ABA researchers have focussed on easily measured variables such as age, initial IQ and language when identifying factors related to treatment response.

In so doing, researchers have avoided broader variables such as parental coping and the stress experienced by children and family members. Several researchers have raised serious concerns regarding ABA approaches and their reported outcomes (Lord *et al.*, 2005; Schreibman, 2000; Smith, 1999). Schopler, Short, and Mesibov (1989) noted that the outcome measures employed in ABA studies such as IQ and school placement (Lovaas, 1987; McEachlin *et al.* 1993), do not reflect true overall functional changes in children with autism. For example, a child may show major increases in IQ over time without improving his or her ability to function in social situations or improve their ability to regulate their behaviour. Moreover, Schopler *et al.* (1989) assert that increases in IQ scores, could reflect increased compliance with testing rather than true changes in intellectual abilities, and school mainstreaming may be more a function of parental and therapist advocacy and changing school policies than increased educational functioning *per se*. In addition, Mesibov (1993) expressed concerns about pre-treatment differences between experimental and control groups in studies of ABA interventions, and about the many domains of functioning in which deficits commonly associated with autism (e.g., social interactions and conceptual abilities) were not assessed. Mundy (1993) raised similar concerns, noting that many high-functioning autistic individuals achieve IQ levels in the normal range, thereby raising fundamental questions about the use of IQ scores to measure the so called “recovery” from autism that some ABA approaches advertise.

4.3.4 Parents as Therapists

While ABA interventions use the principles of discriminative stimulus response and consequence highlighted above, approaches to training parents as therapists differ between specific programmes (Keenan, Kerr and Dillenburger, 2000; Richman, 2001). Some programmes teach parents the use of distinctive treatment procedures in a prescriptive and mechanical way (Boyd and Corley, 2001) while others start by educating parents about the general behavioural principles of behaviourism (Keenan, 2001), such as operant conditioning (Hilgard, 1988) and how these principles were later adapted for use with children with autism (McEachin, Smith and Lovaas, 1993). Proponents of ABA approaches consider it unnecessary to speculate about internal mental processes when explaining behaviour and instead

view that it is enough to know which stimuli elicit which responses. In doing so they hold the belief that the underlying cognitive and emotional issues which challenge people with autism and their families are irrelevant in addressing behavioural challenges (Bandura, 1969). In her review of ABA approaches Chiesa (1994), asserts that ABA therapists not only practice as therapists within the behavioural paradigm but also teach the delivery of programmes to parents within this framework, encouraging them to interpret their child's behaviour as purely a function of environment ignoring any underlying cognitive issues.

4.3.5 Parental Stress and the ABA Approaches

Given that outcome measures of ABA approaches have excessively focussed on IQ as discussed above, there has been limited investigation into the experience of stress and the coping styles employed by parents conducting ABA home-based interventions. Two studies examined the question of whether parents' stress levels affect their children's progress in intervention; these used different interventions and measures of stress. Robbins, Dunlap, and Plenis (1991) found an inverse relationship between the levels of parental stress at the time of programme entry and the progress that was demonstrated by 12 children with autism in a pivotal response type behavioural program. Osborne, McHugh, Saunders, and Reed (2008) examined the effect of parental stress on the outcomes of different types of teaching interventions for 65 children with autism who were divided into four groups, based on the levels of time intensity of their intervention, and on their parents' stress levels. While educational and intellectual gains were observed across all 4 groups, initial parental stress had a negative impact on child outcomes for high time intensity interventions.

Many of the studies that have explored stress in parents who are employing ABA approaches have been conducted by proponents of the ABA approach and have claimed that the intervention can in fact reduce stress in families of children with autism by improving the development of intellectual functioning (Smith, Buch and Gamby, 2000). However, many of these studies have methodological issues and/or contradictory results. For example, Schwichtenberg, and Poehlmann (2007) studied

the impact on mothers of children with autism where an ABA programme had been in place for a period of 6 months. The authors found comparative rates of depression in the mothers of the intervention group with those in mothers of children with autism in general. While mothers reported fewer depressive symptoms when their child was both older and participated in more ABA therapy hours, they also reported more personal strain when the mothers themselves were involved in the delivery of their child's programme. Studies such as this raise a number of questions regarding the relationship between parental stress, coping and interventions such as ABA, which seek solely to focus on the child. The study described above used a relatively small sample (n=41) of mothers in families engaged in ABA programmes. Moreover, while the authors assert that maternal depressive symptoms were less when their child was engaged in more therapy hours, the study fails to take into account that those families who were engaged in more intensive intervention were also those which made greater use of external therapists, thus providing mothers with respite from delivering care. In addition, no comment is made regarding child compliance and motivation. It is therefore difficult to assert that reduced maternal depression is a consequence of increased access to ABA therapy as it can just as easily be said that those children who engaged more were more motivated to do so and were on the whole more compliant.

4.4 Stepping Stones Triple P and Triple P Programmes

The Stepping Stones Triple P programme (SSTP) is a multilevel system of parenting intervention designed to improve the quality of parenting advice available to parents of children who have a developmental disability (Sanders, Mazzuchelli and Studman, 2004) SSTP represents a parallel version of the core Triple P-Positive Parenting Programme, which was developed for children who are developing typically (Sanders, 1999). The approach is described as a multilevel programme as it includes intensive individually delivered face-to-face interventions, group interventions, more cost and time effective brief interventions, large group seminars and media based interventions (Sanders, 1999) and is based on a number of contemporary theoretical perspectives in psychology including learning theory and applied behaviour analysis (Sanders, 1999)

Within the Triple P approach parents are taught 25 strategies based on the following: incidental teaching, (McGee, Krantz, and McClannahan, 1985); backward and forward chaining, (Hagopian, Farrell, and Amari, 1996); teaching your child to communicate what they want, (Tait, Sigafoos, Woodyatt, O'Reilly, and Lancioni, 2004); brief interruption, (Azrin, Besalel, Jamner, and Caputo, 1988). The 25 strategies are incorporated into five levels of intervention on a tiered continuum of increasing strength with the aim of catering for the different levels of support that families require (See Figure 3).

Level 1: A universal parent information level involving media and communication strategies.

Level 2: A brief selective intervention level delivered through primary care services.

Level 3: A preventive intervention level targeting parents who have mild and relatively discrete concerns about their child's behaviour or development.

Level 4: A more intensive prevention intervention level targeting parents who have children with high-risk detectable problems, but do not yet meet diagnostic criteria for a behavioural disorder.

Level 5: An enhanced family behavioural intervention level for families where parenting difficulties are complicated by other sources of family distress. It extends the focus of intervention to include focus on marital communication, mood management, and stress- coping skills for parents.

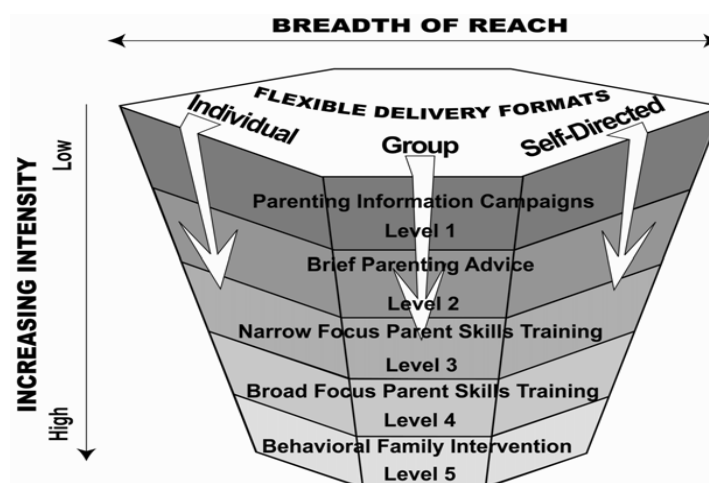


Figure 3. The Triple P Model of Graded Reach and Intensity of Parenting and Family Support Services (Sanders et al., 2004).

The underlying principle of this tiered approach is that there are differing levels of problem behaviours in children that place differing demands on parents. However, implicit in this is the notion that parental stress and coping is linked inextricably to child behaviour.

The evidence base for the original Triple P approach is relatively strong (Sanders, 1999; Sanders, Markie-Dadds, Tully and Borr, 2000), and it has been broadly employed across the UK by both the National Health Service (NHS) and local authority statutory services. In May of 2010 NHS Greater Glasgow and Clyde and Glasgow City Council invested significantly into the programme and made it available to all Glasgow families who had children younger than 16 years (NHSGGC, May 2010, Child Health and Well Being Triple P/ Stay Positive).

4.4.1 Problems with SSTP

Uptake of SSTP approach in the UK is more limited than that of Triple P, as there have been few studies that have evaluated SSTP as an intervention for families with children with autism or other developmental disorders. Whilst Whittingham, Sofronoff, Sheffield and Sanders (2009) reported positive changes in parental rating of behaviour in 59 parents of children with autism, there have so far been no studies conducted outwith Australia. In addition, while researching this thesis the author was unable to identify any NHS Board in Scotland who were currently using the SSTP. In addition to the lack of empirical evidence to support the use of SSTP in families of children with autism, Probst, Glen, Spreitz, and Jung (2010) questioned the social validity of the intervention for children with developmental disabilities. In their evaluation of the approach, they provided 33 masters-level psychology students with documentation from the programme, which outlined some of the behavioural strategies that SSTP employs. All 33 participants rated the strategies of quiet time and time out as lacking in both ethical acceptability and practical applicability. This suggests the need for further studies to not only evaluate the impact of SSTP on child and parent variables, but a more rigorous evaluation of the social validity of some of the treatment components for children with developmental disorders.

4.5 Floortime

Floortime, is a developmental approach developed by Greenspan and Wieder (1997), and promotes social interaction between an autistic individual and an adult. Adults are instructed to follow the child's lead and build on what the child does to encourage further interaction. By following the child's interests and motivations, parents help their child learn how to attend to others, engage in a dialogue, take initiative, learn about causality, and how to solve problems. An adult may purposely make the wrong move so that the child has to direct the adult in how to fix the problem and keep the interaction going. For example, if a child wants to line up blocks, his/her parents will join the child with the intention of developing an affective interaction, rather than demand that the child join them in an activity of their desire as is the case in many educational approaches such as ABA.

Greenspan called the back-and-forth communication between the child and the adult 'circles of communication'. Through such circles, parents can enable their child to connect his/her emotions and intent to their behaviour.

There are five basic steps to facilitate floortime:

1. Observation
 - Observe the child by listening and watching in order to determine how to approach the child
2. Approach – open circles of communication
 - Once a child's mood has been assessed, the adult should approach the child with appropriate words and gestures, elaborating and building on the child's interests
3. Follow the child's lead
 - Be a supportive play partner who is an 'assistant' to the child in the activity of their desire. Allow the child to set the tone and direct the action. This allows the child to take initiative and be assertive. The interaction gives the child a sense of warmth, connectedness, and a feeling of being understood.
4. Extend and expand play

- Allow the child to express their own ideas and ask questions to stimulate creative thinking

5. Child closes circles of communications

- The child builds on the adult's comments and gestures with their own comments and gestures. The child begins to recognise and appreciate the value of two-way communication.

Greenspan and Wieder (1997)

Advocates of developmental approaches such as Floortime have asserted that intervention can change the way parents interact to increase reciprocity and that these changes are correlated with changes in social engagement and in language Gernsbacher (2006). In a randomised controlled trial looking at joint attention and symbolic play in 58 children with autism Kasari *et al.* (2008) found that expressive language gains were greater for treatment groups which used developmental approaches compared with the control group that was based only on behavioural principles.

4.5.1 Problems with Floortime

Literature on the effectiveness of floortime is sparse, and the few studies that exist have significant methodological issues in terms of both sample size and treatment integrity. In one study by Solomon, Necheles, Ferch, and Bruckman, (2007), parents were encouraged to engage their children in floortime for at least 15 hours per week after receiving intensive one-day training. Parents could choose to set aside time for daily structured floortime with their children or apply the floortime principles to time naturally spent together such as during meals, children's baths, or bedtime. Measures were taken using the Functional Emotional Assessment Scale (FEAS), which subscales in both the child and parent domains measure regulation, attachment, behavioural organisation, representational elaboration and emotional thinking. Results showed that 45.5 % of children made good to very good functional developmental progress, but there was no change noted in the parental domain from pre to post intervention, suggesting that parental appraisals of child behaviour remains unchanged by the intervention.

The Floortime approach of Greenspan and associates (Greenspan and Wieder, 2006) has a theoretical foundation related to the connection between affective development and the development of skills in other areas which is not exclusively specific to autism. This emphasis on individualisation rather than a standardised, tightly manualised approach has meant that no rigorous empirical studies on Floortime have been published in peer-reviewed journals.

4.6 Son-Rise

The Son-Rise Programme (SRP) (also known as the Options programme, in the UK) was developed by the parents of a boy (Raun) with autism in the early 1970s, who provided one-on-one intervention (child-adult dyads), in a distraction-free, naturalistic environment (Kaufman and Kaufman, 1976). The success of the approach prompted the family to establish a commercial enterprise called the Option Institute, which is why the programme is also referred to as Options. The approach is intended to promote spontaneous, child-initiated social interactions, with following the child's lead being core to the approach. All social interactions and subsequent prompting by an adult occur only after the child initiates interaction with a communicative act such as head orientation and/or eye- contact, a gesture or verbalisation. An important corollary of following the child's lead is contingent imitation, i.e. imitating (or "joining") the child's activities or movements, which has been shown to increase social-communicative behaviour when used as part of developmental interventions Lewy and Dawson, (1992).

The Son-Rise programme is normally delivered by parents and volunteers in the family home, once the parents have received training from the Options Institute. One adult at a time works with the child with autism, usually in a special playroom which parents are advised on how to develop within the family home, and is conducive to offering the child objects of interest that may engage their attention by developing the relationship through interaction the adult is able to use the child's own motivation to teach new skills based around the child's interests. The adult may have to learn to communicate with the child in a way that suits the child. For example, they may need to vary the pitch and level of their voice or restrict their language so that it is easier to understand. So the adult may say 'Dinner?' rather than

‘Do you want some dinner?’ The approach also requires the adult to make eye contact at every possible opportunity because it is felt that the more a child looks, the more they learn.

The evidence for the approach is generally limited to anecdotal accounts, which on the whole are fairly positive and originate from both parents and professionals alike (Kaufman, 1994). However, in the development of this thesis the author carried out a review of the literature discussing parent-mediated interventions and was unable to find any scientifically valid or reliable research trials that evaluated the SRP approach. In addition, in her evaluation of SRP, Williams (2006) found that although it proved possible to produce a profile of intervention use, findings indicated that the programme is not always implemented as it is typically described in the literature, raising questions as to how the intervention can be properly evaluated.

4.6.1 Problems with Son-Rise

There have been a small number of case studies published on the use of the SRP and some families have reported that it has helped them develop a more positive attitude towards their child’s disability (Kaufman, 1981; MacDonald and MacDonald 1991). However, the potential demands which implementation of the programme may place on families have also been documented and studies have shown that the demands of implementing the programme can increase parental stress (Jordan and Powell 1993; Lynch 1998). In their longitudinal questionnaire-based study of the Son-Rise Programme, Williams and Wishart (2003) explored a number of potential positive and negative effects for the family and how these changed over time in relation to child characteristics and how the programme was implemented. In assessing the impact of the programme they found more drawbacks to intervention than there were benefits with a significant impact upon parent-child relationships. Moreover, the study found that over time parents began to form negative views of their child with autism due to the demands which the programme made, resulting in potential disruption to child parent bonding.

4.7 TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children)

TEACCH is a clinical service and professional training program, based at the University of North Carolina. The TEACCH approach is called “Structured Teaching” and it combines both behavioural and developmental approaches. Structured Teaching is based on evidence and observation that individuals with autism share a pattern of neuropsychological deficits and strengths that TEACCH refers to as the ‘Culture of Autism’ (Mesibov, Shea and Schopler, 2005), and includes the following characteristics:

1. Relative strength in and preference for processing visual information (compared to difficulties with auditory processing, particularly of language).
2. Heightened attention to details but difficulty with sequencing, integrating, connecting, or deriving meaning from them.
3. Enormous variability in attention (individuals can be very distractible at times, and at other times intensely focused, with difficulties shifting attention efficiently).
4. Communication problems which vary by developmental level but always include impairments in the initiation and social use of language (pragmatics).
5. Difficulty with concepts of time including moving through activities too quickly or too slowly and having problems recognising the beginning or end of an activity, how long the activity will last, and when it will be finished.
6. Tendency to become attached to routines and the settings where they are established, so that activities may be difficult to transfer or generalise from the original learning situation, and disruptions in routines can be uncomfortable, confusing, or upsetting.
7. Very intense interests and impulses to engage in favoured activities and difficulties disengaging once engaged.
8. Marked sensory preferences and aversions.

(Mesibov and Howley, 2003)

4.7.1 Mechanisms of structured teaching

The essential mechanisms of Structured Teaching are (a) structuring the environment and activities in ways that are understandable to the individual; (b) using individuals' relative strengths in visual skills and interest in visual details to supplement relatively weaker skills; (c) using individuals' special interests to engage them in learning; and (d) supporting self-initiated use of meaningful communication (Sheehy, 2001).

4.7.2 Parent as therapist

A main focus of the TEACCH programme is to teach parents how to assess and implement individualised supports for their child, with TEACCH centres providing parents of children of all ages opportunities to learn these strategies in 4 to 8 weekly sessions supervised by staff in the clinics. As such, the TEACCH approach does not make any distinction between parent and therapist. Parents are trained to deliver the approach at home in the same way that teachers are taught to deliver the approach in a school setting. The only empirically evaluated study of parents as therapists using the TEACCH approach is that by Ozonoff and Cathcart (1998), who implemented the TEACCH programme by training a group of 11 parents of children with autism aged 2- 6 years to implement the programme at home. This was achieved by one therapist working directly with the child, demonstrating tasks and modelling teaching skills to the parent, the parent watched on from behind a one-way mirror with another therapist, who explained the techniques in detail and provided emotional and other support. Following this observed session specific activities and methods were written down in a formal programme by the therapists and sent home with parents for implementation. During the following week, parents were encouraged to spend half an hour per day working with their child in the home, using the same materials and techniques as in the clinic session. Upon their return to the clinic a week later, they demonstrated to the therapists what they had been doing at home, while therapists provided suggestions for fine-tuning and modifying activities as needed. The mean number of treatment sessions lasted 10 weeks. Children in the treatment group reported significant improvement in cognitive and academic skills

relative to a control group of 11 parents who were on a waiting list protocol. However, the study ignored parental variables and there was no overall assessment of parental characteristics.

4.7.3 Problems with TEACCH

Whilst the TEACCH programme represents a ‘model’ for therapists and families, research has been critical of its lack of consideration of different social and family contexts (Panerai, Ferrante, and Zingale, 2002). In his study following 15 children from waiting list through treatment period, Short (1984) noted during home observation that TEACCH did not make any adaptations for the demands on parents becoming therapists and that parental stress did not improve as a result of the home based programme. Moreover, Howlin (1997) raised concerns about the influence that staff member skills and experience may have on intervention outcomes with there being variability of the delivery of the programme due to the relative experience and knowledge of the TEACHH staff member coaching the parent.

4.8 Chapter Summary

There are currently no parent-mediated interventions for families of children with autism where the primary focus is on parental stress reduction. With the exception of SSTP (which has a very limited evidence base) all other interventions focus on teaching parents how to deliver programmes to their child where the acquisition of skills is the primary focus. In doing so, these interventions negate the burden on parents of delivering their approach and pay little attention to the role of parental stress. The five approaches outlined above exemplify this point. The focus of intervention on improvement in symptomology in the child with autism has yielded very little in terms of evidence, a report from the Autism Task Force in Maine, U.S. (2000) illustrates this point. It concludes that there is no peer reviewed, scientific evaluation for treatments such as Floor time (Greenspan, 1998), that the Son Rise Program (Kaufman, 1997) is “‘without scientific evaluation of any kind’”, and that the existing evidence for the effectiveness of TEACCH is “‘inadequate’”. This narrow focus of intervention has led to significant gaps in our understanding of

what happens to parents who adopt parent-mediated intervention and has had little impact on the well-being of families as a whole.

Prizant and Rubin (1999) suggest that to achieve greater generalisation and maintenance of skills the knowledge base for intervention programmes should be derived from a combination of different sources, including theory (developmental, learning, family systems etc), clinical and educational data, and knowledge about best practice and should be implemented in an approach that is family centred. Moreover, Marcus, Kuncie and Schopler (1997) contend that the development of management strategies that can be implemented consistently but in ways that do not demand extensive sacrifice in terms of time, money or other aspects of family life, seem the most likely to offer benefits for all family members.

Osborne *et al.* (2008) examined how parenting stress counteracted the effectiveness of early teaching interventions, their study found that early teaching interventions produce fewer gains when parents report high feelings of parenting stress, especially when the teaching intervention had a higher time-input (Osborne *et al.*, 2008). It is also important to note that higher levels of parenting stress may influence parenting behaviours, which in turn can affect the child's outcomes.

In contrast to the approaches outlined in this chapter, the intervention developed within the thesis places emphasis on the development of knowledge and understanding within parents. The design of the intervention draws on the evidence that parental stress is influenced by how parents appraise their child's behaviour and the meaning that this holds for them. This is a radical departure from what has largely been held up as the standard model of parent-mediated intervention, as it does not necessarily require any observation or direct work with the child or the parent interacting with the child. Moreover, there is no requirement placed upon parents to deliver a programme within a prescribed framework or measure success based on criteria that is linked to child behaviour or the acquisition of skills.

Chapter Five

Hypotheses and Potential Components of a Parent Mediated Approach

Hypotheses of the study

Hypothesis 1. It is predicted that parental stress related to child characteristics would reduce resulting from the intervention.

Hypothesis 2. It is predicted that parental stress related to parent characteristics would reduce resulting from the intervention.

Hypothesis 3. It is predicted that parental coping styles would change as the intervention allows parents to explore their own coping resources when considering behavioural change.

5.1 The Value of Parent-Mediated Approaches

The World Health Organisation's International Classification of Functioning, Disability, and Health framework highlights the significance of environment health and well-being and the important relationship between the health of parents and the child (World Health Organisation, 2001). This follows a paradigm shift in health care service delivery away from child-centred models focusing primarily on treating the child's disability towards more family oriented services and family-centred well-being (Rosenbaum, King, Law, and Evans, 1998). As posited by Brehaut *et al.* (2004), family-centred policies and services that put into consideration the health of caregivers are expected to benefit the wellbeing of both caregivers and their families. This philosophical position has been adopted in the Scottish Government strategies *The Carers Strategy for Scotland (2001- 2015)*, and the *Scottish Strategy for Autism (2011)*. In their Cochrane Review of parent mediated interventions for young children with autism, Diggle and McConnachie (2009), explicitly state the value of involving parents within programmes, specifying that home based intervention not only increases the development of relevant skills, in the child but also supports the development of parental confidence. In addition, the impact of parental well-being on child behaviour, is well established within the literature and several studies have

noted improvements in the children's behaviours resulting from reductions in parenting stress (e.g., Bitsika and Sharpley 2000; Engwell and Macpherson 2003; Harris, Handleman, Arnold and Gordon, 2000; Lovaas and Smith 2003). However, despite this evidence and the changes in public health perspectives, parent-mediated interventions for parents of children with autism continue to focus on training parents to attempt to reduce the behavioural symptoms of autism in their child. Moreover, with the exception of the SSTP approach described earlier, almost all parent-mediated interventions are exclusively aimed at parents of young children with little consideration of parents of children of late primary or secondary school age.

5.2 A Psycho-Educational Approach

This study utilises a psycho-educational approach to address the stress experienced by parents of children with autism. Anderson (1980) is generally credited for the development of psycho-education as an intervention for individuals experiencing psychological distress. In her work with patients with schizophrenia Anderson developed the psycho-educational approach to address issues of *expressed emotion* in families as an adjunct to other treatments. Her work demonstrated that by combining education about mental disorder with an enhanced understanding of the psychological issues within the family, the impact of psychological constructs such as *expressed emotion* can be reduced.

Core to psycho-educational principles is the notion that education has a role in emotional and behavioural change. With an improved understanding of the causes and effects of the problem, psycho-education broadens the person's perception and interpretation of the problem, and this refined view positively influences the individual's emotions and behaviour. The intervention in this thesis aims to develop parental understanding of their child's behaviour educating them about the underlying cognitive issues faced by children with autism, and the impact that has on child behaviour. By doing so it is hoped that the intervention will positively influence parental views of behaviour which they have found challenging. In addition, the intervention teaches parents that by understanding the function and meaning behind their child's behaviour they can use the behavioural technologies of

Positive Programming to enable their child to have their needs met in socially valid means.

The following sections in this chapter provide an overview of the conceptual areas that have been adopted within the educational and psychological components.

5.3 Parental Understanding as a Component of Intervention

The perceptions and expectations that parents have of their child's behaviour influence the type and styles of parent-child interactions (Marfo, 1984; Mahoney, O'Sullivan, and Dennebaum, 1990). Moreover, higher levels of stress experienced by parents of children with autism may result in less positive parental perceptions of their children (Forehand, Wells, and Greist, 1980) and negatively affect the quality of early parent-child relations (Baker, Landen, and Kashima, 1991). Given that parents of children with and without developmental disorders routinely assign meaning and intentionality to their child's behaviour (Bugental, Blue, and Cruzcosa, 1989; Dix, 1993; Dix, Ruble, and Zambarano, 1989; Feldman and Reznick, 1996; Walden, Urbano-Blackford, and Carpenter, 1997), it seems reasonable then to suggest that an important part of any intervention should be an understanding of the causes of behavioural presentation which in turn influence parent perceptions and interpretations.

As discussed earlier, knowledge can be seen as causal attributions that interact with meaning within the appraisal process of a stressful encounter to predict emotional outcomes (Lazarus, 1991). Therefore, in developing parental knowledge of their child's disability, intervention can influence how parents derive meaning when being confronted with difficult situations by their child with autism. A key outcome for both Floortime and Son-Rise is that parents derive meaning from their child's behaviour and use that as a basis of interaction. Within both approaches parents are encouraged to appraise behaviours such as repetitive movement not as behaviours' that must be reduced, but rather opportunities to develop interaction. Similarly, the developmental components of the TEACCH programme aim to develop therapist and/or parent understanding of certain behaviours as being linked to the core deficits in autism and their uneven profile of development. While

TEACCH does not prompt parents to use certain behavioural presentations for interaction in the way that Floortime or Son-Rise do, it does aim to develop parental understanding of why their child may present in unusual, repetitive or pedantic ways. Proponents of the TEACCH approach believe that parent training through education can achieve the following: (1) the enhancement of parents' psychological resources, by strengthening self efficacy and sense of coherence (2) the enhancement of social resources, by learning from other parents how to use community supports; (3) the enhancement of behavioural coping skills, specifically by acquiring parenting strategies and skills; (4) the strengthening of adaptive emotional coping abilities when discussing emotional experiences regarding the child with other parents, possibly resulting in the reappraisal of stress and demands; (5) the enhancement of family adaptive functioning, in terms of reduced parent stress, strengthened parent health, and improved parent-child relationships (Marcus, Kuncie and Schopler, 2005).

5.4 Positive Programming

Positive programming (PP) or Positive Behaviour Support strategies such as those described by Donellan, La Vigna and Negri-Shoultz (1988), have been shown to be effective in curbing the impact of many challenging behaviours associated with autism and learning disability (Horner *et al.*, 2005). While PP shares its' theoretical origins with ABA, it differs in that its overall aim is the application of behavioural approaches to social problems that limit the child's ability to access community resources. A signature of the PP approach is its committed focus on fixing environments, not people (Biglan, 1995).

Positive Programming utilises behaviour technologies that examine the meaning of the behaviour to the person and then seeks to identify more socially valid means of having that need met. For example, a PP approach to self-injurious behaviour in a child with autism may be to observe in which context the behaviour presents and identify the function of the behaviour relative to the context. Once the function has been identified the PP approach advocates teaching the child an alternative and socially valid means of having that need met. There is a strong evidence base for the behavioural technologies employed by PP as they share their origins with ABA. Methods such as shaping, fading, chaining, prompting, and

reinforcement contingencies as well as a wide array of procedures for reducing problem behaviour are employed within the approach (Sulzer-Azaroff and Mayer, 1991). The concepts of setting event and establishing operations, and the notions of stimulus control, generalisation, and maintenance (Chance, 1998; Miltenberger, 1997) are adapted from the behaviourist literature for use in natural community settings to inform intervention strategies, and define what constitutes a successful outcome (Carr, 1997)

5.4.1. PP and its use with Parents

Rather than teaching parents to deliver discrete trials or behavioural protocols repeatedly for many hours a week the PP approach advocates observation and measurement of behaviour to identify its meaning and then to provide alternative means of reinforcement that meets the child's needs (Iwata, Dorsey, Slifer and Richman, 1982). This teaching of *functional equivalence* is central to PP and reinforcement is used as a means of shaping behaviour, rather than eliminating it. The PP approach to challenging behaviour does not assert that it can resolve all behavioural issues, nor does it define any single methodology (Horner et al, 1990). Instead the approach advocates a group of behavioural techniques which are “non aversive” in nature (Horner *et al.*, 1990) and which should be used as part of holistic supports that allow the individual to have their needs met and promote community inclusion (Durand, 1988). In describing how PP may be used clinically, Anderson, Russo, Dunlap, and Albin, (1996) outline how collaboration is central to case formulation, goal setting, intervention selection, and on-going programmatic change made within a collegial and egalitarian model of operation. Thus, rather than have a prescriptive training programme which does not take account of individual differences and context, advocates of the PP approach define meaningful training as involving *in vivo* problem solving within real-life such as the family home or service (Anderson and Adams, 1996).

5.5 Motivational Interviewing

Motivational interviewing (MI) is an egalitarian, empathic intervention that adopts specific techniques and strategies, such as reflective listening, shared decision making, and agenda setting. A primary aim of motivational interviewing is to assist individuals in working through their ambivalence about behaviour change. This approach appears to be particularly effective for individuals who are initially less ready to change (Miller and Rollnick, 1991). The use of Motivational Interviewing in facilitating behaviour change in patients is well documented in areas concerned with addiction and chronic illness such as asthma, diabetes and coronary heart disease (Barnett, Monti, and Wood, 2001; Monti *et al.*, 1999; Stott, Rollnick and Pill, 1995; Knight, McGowan, Dickens and Bundy 2006).

5.5.1. MI Technologies and Strategies

The technologies and strategies involved in MI are designed to complement the spirit of the approach which is the context or interpersonal relationship within which the techniques are employed (Miller and Rollnick, 2009). Therefore, the strategies and tools which MI utilises focuses on supporting the client with resolving their issues of ambivalence and promoting confidence to address behaviours they have appraised as challenging (Rollnick and Miller, 1995). There are five early methods within the MI approach commonly referred to as “OARS” which are designed to help clients explore and resolve their ambivalence about making changes and are outlined below:

Five Early Methods (Miller and Rollnick, 2002)

- Open Questions: Using questions that cannot be answered with one word. This keeps the focus broad and invites clients to explore topics extensively. Open questions are viewed as door openers, providing opportunities to use other early methods. Over-reliance on questions, even open questions, is discouraged.
- Affirming: Voicing support for the client’s strengths and personal efforts, within the context of societal and cultural norms. This increases the client’s confidence and self-efficacy.

- **Reflective Listening:** Responding to what the client says in a way that conveys understanding of the client's feelings or the meaning of the client's statements. This is considered to be one of the most important and sophisticated skills in MI; it includes paraphrasing what the client said, or guessing about the emotional impact on the client. Reflective listening is used to test the accuracy of the therapists understanding. It is used to explore both sides of a client's ambivalence and is used to reinforce change talk.
- **Summarising:** Using longer reflections to summarise what the client has discussed over a period of time. This is often used to reinforce important parts of the discussion, to link ideas with previous discussions, or to suggest a transition to another topic.
- **Methods for Evoking Change Talk:** A variety of strategies are used to elicit "change talk" from the client. Change talk includes statements supporting or indicating desire for change, ability to change, reasons for making a change, and reasons not to stay the same. Strategies include but are not limited to eliciting from the client discussions of personal values, goals, strengths; the "good and the not so good" ideas about changing or not changing; and looking forward or backward to compare life with and without changes.

As the client grows in confidence MI advocates the use of strategies that enhance the identification of behaviours that the client can address relative to the importance and meaning to the client, and the degree of confidence the client has in being able to make change. One commonly used strategy is Rollnick's or the Importance ruler (Butler *et al.*, 1999; Rollnick, Mason and Butler, 1999). Figure 4 below illustrates how it can be used with clients in identifying and addressing specific behaviours.

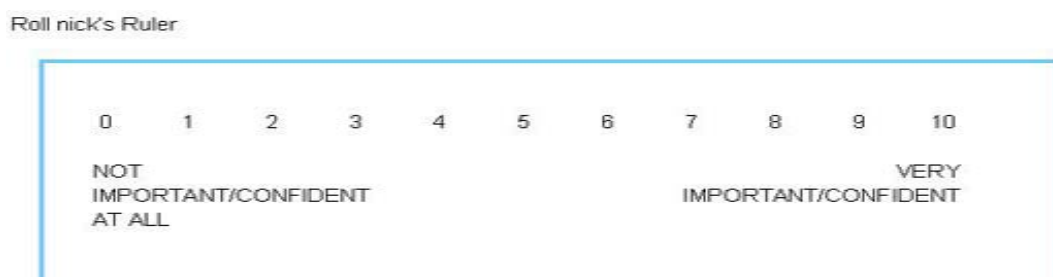


Figure 4 Rollnick's Ruler (Rollnick, Mason and Butler, 1999)

Clinicians typically open with the importance ruler (Figure 4), by asking “How important is it for you right now to change [target behaviour]? On a scale of 0 to 10, what number would you give yourself?” Clients then provide a number (X). The next questions follow, “Why are you at X and not at 0?” and “What would need to happen for you to get from X to X + 1 or X + 2?” Once the importance of change has been explored in this manner, the conversation can shift to questions regarding self-efficacy or confidence around change, using the confidence ruler. “If you did decide now to change [target behaviour], how confident are you that you could do it?” clients again provide a number (X). And clinicians follow with the same questions as before: “Why are you at X and not at 0?” and “What would need to happen for you to get from X to X + 1 or X + 2?”

5.5.2. MI Parent child interaction

More recently, clinicians have thought to extend this approach where behaviour change has focused on both child and parental behaviours (Resnicow, 2002). In their recent study of parents of children with schizophrenia (n=53), Keet *et al.* (2012) found that MI was effective when used with parents to address cannabis use in their adolescent children. The researchers noted that those parents who received MI felt more confident in addressing behaviour and demonstrated increases in self-efficacy following intervention. Many parents of children with physical disabilities and chronic health conditions experience a sense of doubt and limited efficacy in shaping their son/daughters behaviour (Berg-Smith *et al.*, 1999). Some studies have highlighted parents’ feelings of resistance to implementing behavioural change as a result of lack of confidence in the process, and in their own abilities (Resnicow, 2002; Bristol, 1984).

Earlier in chapter 3, this thesis discussed the role that locus of causality plays in the appraisal process and ultimately what emotions would be experienced as a result of that causality (*cognitive-motivational-relational theory*). If MI allows parents to identify those behaviours, which they feel they can exert influence on for the benefit of the child and the family unit, then it will influence the appraisals

formed by parents. If the parent is successful in their efforts then this will in turn affect future appraisals of child behaviour. Within this framework it would seem that MI may offer a potential mechanism for the parent to form appraisals and ultimately develop healthy coping styles relative to context, child behaviour and parental perceived control.

Chapter Six

Methodology

6.1 Rationale

The aim of this study was to assess the impact of a psycho-educational intervention designed by the author for parents of children with autism. Many other interventions ignore parent characteristics and focus on observable change in child behaviour. In contrast, the psycho-educational intervention evaluated in this study is exclusively concerned with parental appraisals of their child's behaviour in the context of day-to-day interactions. The Transactional Model of Stress and Coping (Lazarus and Folkman, 1984) describes the dynamic process of the stress transaction and has been used to describe the stressful experiences of parents of children with autism (Hastings et al, 2005). This model of stress and coping, as well as the aim of the study to intervene with parental appraisal of their child's difficult behaviour and the resulting stress, has underpinned the choice of measures.

6.2 Participants

6.2.1 Recruitment

Parents were recruited from three local authority areas in Scotland (Edinburgh City, Aberdeenshire and Falkirk). These local authority (LA) areas were identified as they represented a mix of remote rural, accessible rural, accessible small town and large urban area (Scottish Government, 2009), were within travel distance from National Autistic Society (NAS) offices and had expressed interest in the study when it had been proposed at a national forum¹.

The Study was given a grant of £125,000, which was the maximum grant that could be provided from the Scottish government health group and which would allow for the parents of sixty one children to participate. The three participating LAs identified a liaison person² who distributed participant recruitment letters (appendix 1, p.125) to the households of children with autism within the LA area and who were identified on a shared Education, Social Work and Health database.

¹ This was an event jointly organised by Strathclyde University and the Scottish Government for the launch of the Autism Toolbox for all schools in Scotland and at which most of the LA's in Scotland were represented

² The liaison person was a senior manager within Education Department of the local authority who either had a remit for autism or additional support needs and who was able to liaise with and inform other statutory agencies such as Social Work and Health as to the nature of the study.

All three LAs reported having this system of tracking children diagnosed with an autism spectrum disorder, and recruitment letters were forwarded to the LA liaison person to forward to parents in their area with a stamp addressed envelope enclosed to return to the LA liaison person. The LA liaison person then forwarded these on to the author. Table 1 below shows the number of responses from each LA area and the number of participants selected to take part in the study representing 20 families from each respective LA area.

Table 1: *Number of respondents, and numbers selected*

	Aberdeenshire	Edinburgh City	Falkirk
Number of respondents	N=55	N=35	N= 23
Number Selected	N=25	N=27	N=21

Participants were selected from respondents using a simple random sampling technique involving assigning each individual or pair of individuals (if they were from the same family), a number that was then drawn from a hat. For those selected a letter providing information about the study (appendix 2, p.126) and a letter of consent (appendix 3, p.128) was issued prior to attending the first workshop. In addition, those who had responded but were not selected were written to (appendix 4, p. 129) informing them that that they had not been identified by the random sampling technique, but that their names would be passed on to the LA liaison person who would keep them informed of any future parent programmes. Of the seventy three consent forms which were sent out to the selected participants, seventy one were completed and returned, making the overall number of final participants seventy one.

6.2.2 Inclusion/Exclusion Criteria and Issues with a Control Group

Inclusion criteria

Parents of a school aged child with a primary diagnosis of autism where the child is living at home, where the parents are not currently engaged in any other

home based programme, and where the parents are not engaged in any talk based intervention to assist with stress, anxiety or depression.

Exclusion Criteria

Parents were excluded from the study if their child was attending a residential service (excluding respite), parents who are currently in receipt of counselling or any talk based intervention for the treatment of stress, anxiety or depression or where they are currently engaged in any home-based or parent-mediated intervention.

Control Group

This study received funding from the Scottish Government to investigate whether the approach described could be of assistance in reducing stress in parents. There were certain parameters set out in the funding agreement that have placed limits on the methodology. One of these was the timescale in which the money was to be used and feedback provided to the Government. The timescales laid out was that of 18 months. A significant limitation of the study is the lack of control group. While a waiting list control group would have been the ideal conditions under which to carry out the research this was not possible within the time frames provided. Moreover, neither those recruited to conduct motivational interviewing with the families nor myself were freed up from our full time positions to carry the work out. During the period of the study and the write up we were still in our substantive posts placing further limitations on what could be achieved.

6.2.3 Participant Characteristics

The sample comprised 71 parents of children with autism from three local authority areas in Scotland. Of the 71 parents who participated in the study 86% (n=61) were female and 14% (n=10) were male. Parents were defined as either the biological parent of the child or the partner of the biological parent of the child

residing in the family home with the parent a summary of marital status of parents participating in the study is set out in table 2 below.

Table 2 *Marital status of participants*

Marital Status	Number	Gender
Married	35	Female
Married	5	Male
Single	5	Female
Divorced	18	Female
Co-habiting biological parent of child	3	Male
Co-habiting biological Parent of Child	3	Female
Co-habiting no relation to child	2	Male

Table 2 above shows the marital status, sex and relative number of participants selected for the study. Table 3 below shows the numbers and gender of those who were participating with their partner.

Table 3 *Participating with partner*

Gender	Participating with Partner	Participating on own
Male	10	0
Female	10	51

6.2.4 Child Characteristics

Participants were not asked to disclose their ages for the purpose of the study. However, child ages were recorded as part of the procedure for administering one of the measures. Child ages ranged from 6 to 12, table 4 below shows the relative number of children for each each age.

Table 4. *Child Age*

Child Age	Frequency
6	5
7	11
8	13
9	13
10	7
11	8
12	4

Of the 61 children represented 85 % (n=52) were boys and 15% (n=9) were girls. The eldest boy was 12 years of age and the youngest boy was 6. Within the girls, the eldest was 11 years of age and the youngest was 8.

6.3. Procedure

6.3.1. Ethical Issues

The research was approved by both the Queen Margaret University and National Autistic Society Ethics Committees. Data were anonymised by using a numerical coding system to represent individual participants. The numerical coding was carried out by an administrator who had been funded for 5 hours per week to assist with the study. The administrator had no contact with any of the participants or with the local authority representatives. Encoded cases and anonymised questionnaires were passed onto the researcher for scoring and data analysis. Completed questionnaire and notes were held within a locked filing cabinet that only the researcher had full access to. Family facilitators had access to the notes pertaining to the parents they were directly supporting. Numerical data was entered into an SPSS file that was held on one computer and the file was password protected.

6.3.2 Development of Workshops

The workshops and parent manuals were developed prior to the recruitment of participants. Workshops had to provide parents with knowledge and skills that could influence how they appraised their child's behaviour and identify any behaviours that they felt they could address. Moreover, as different parents will form different appraisals of their child's behaviour it was considered that strategies described within the workshops should be flexible enough to accommodate the different experiences of individual family systems, be able to draw upon the resources of family members, and be adaptable for use within a home setting. In so doing, the intervention encouraged parents to develop strategies that they felt appropriate for managing behaviour within the context of their family. Given the considerable debate regarding the efficacy of any specific approach or intervention in managing problem or difficult behaviour of children with autism (Campbell, 2003), the SIGN guideline *Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders* (SIGN, 98) was used as a reference point which influenced some of the approaches that may be of use to parents in managing difficult or challenging behaviour. The guideline recommends that behavioural interventions should be used to address a range of behaviours and reduce

their impact in terms of severity and frequency. The guideline grades this recommendation as a Grade B, meaning, “that there is a body of evidence to support this” (SIGN, 98), including high quality systematic reviews. As such, Positive Programming or Positive Behaviour Support (discussed in the previous chapter), with its emphasis on social validity was identified as a framework to introduce to parents that they may find useful in interpreting and addressing child behaviour.

Workshop One

The content of *workshop one*³ (appendix 5, p.130) was as follows;

Understanding autism as a neuro-developmental disorder

- What is autism?
- What is a developmental disorder?
- What is the Autism Spectrum?
- What are the main theories of differences in thinking styles?

The Meaning of Behaviour

- What is the function of behaviour?
- How can we analyse behaviour?
- What influences/reinforces behaviour?
- How can we shape behaviour?

A very simple tool for assessing parental knowledge was developed, to be delivered in the style of a quiz⁴(appendix 6, p.131). The quiz was developed to “debunk” myths regarding autism while developing parental understanding of the concept of developmental disorder and how that relates to the behaviours observed in children with autism. The quiz was to be issued to participants at the start of the workshop, with the delivery of answers forming part of a discussion that would encourage parents to share their experiences of their child’s behaviour and the uneven profile of cognitive development, characteristic of autism. The quiz was also used to ensure that all parents were at the same starting point for the rest of the day

³ The slides in the workshop were used as a focus of discussion, much of the teaching related to practical examples from the author’s own experience

⁴ While facilitating parental knowledge the quiz was also used as an icebreaker at the start of the workshop following introductions

and the questions covered within it related to the slides, which were about to follow. The link between common behavioural symptomology expressed in individuals with autism and their uneven or “spikey” cognitive profile was linked through illustrations of behaviour of developmentally and cognitively young children. Many practical examples were built into the delivery of the programme that demonstrated this link and parents would be given scenarios which contrasted typical approaches to those which considered the cognitive styles of children with autism. Through facilitated discussion participants were encouraged to discuss the changes they had observed in their children from infancy through toddlerhood and into childhood. It was hoped that parents would provide examples of differences in development between their child with autism and other children in the family as this would provide an opportunity to contrast and discuss the different trajectories of development that is characteristic of autism. While it was thought that some of the language may be difficult for parents the author considered it important that parents were familiar with terms such as theory of mind, weak central coherence and executive function as it would provide a label to the behaviours they observed in their children.

Assisting parents to identify the function of their child’s behaviour was a central tenet of the workshop with the notion of shaping behaviour as a means of intervention providing more realistic outcomes to behavioural support rather than elimination of challenging behaviour. It was thought that this would challenge many parent’s thinking as it would require them to review how they are currently managing behaviour and what meaning they have given their child’s difficult behaviour. An overall aim of the Parent Programme was to change parental stress, which was derived from child characteristics such as their challenging behaviour. Therefore, the entire afternoon of workshop one focused on interpreting meaning, giving examples from the author’s experience and also encouraging parents to voice their own experiences and what meaning they had given to previous episodes. As such the workshop was designed to have the following key concepts as desired learning outcomes for parents: *functional equivalence*⁵ (the ability to derive the same satisfaction from a replacement activity that is more socially valid), *antecedent control* (the controlling of events or identification and removal of stimuli that would

5 This relates directly to the literature on positive programming

otherwise cause distress) and *reinforcement of desired behaviour* (the provision of reward for behaviour which is socially appropriate).

Punishment and consequence are often associated with parenting styles in western culture, as are styles which can be overly permissive (Greenwald, Bank, Reid, Knutson, 1997). Therefore the use of appropriate discipline with children is often the source of much stress within families (Woolfson, and Grant, 2006). Irrespective of disability it is typical that parents may respond to the behaviour of their child in a manner influenced by culture, their own childhood, the views of parents and peers, and the experience of raising other children. The workshop was designed to explore parental views of discipline by using behavioural scenarios to prompt discussion. Moreover, by airing their views on how they would address behaviour the workshop hoped to address parental misconceptions that children with developmental disorder would consistently respond to consequence orientated approaches in the same manner that typically developing children would.

The role of parental discussion and parent experiences was thought to be highly important in the delivery of the workshop and it was felt that the workshop should end with parents summarising their own learning. To facilitate this, the final slides engaged parents in an activity that encouraged them to think of behaviour in its broadest sense and rather than just having to respond to behaviour which is challenging. To that end the workshop concluded with an activity that encouraged parents to assess the meaning of their own behaviour, reinforcing the point that all behaviour, challenging or not has meaning.

Workshop Two

The content of the workshop 2 (appendix 7, p.132) was as follows:

Attention

- The nature of attention
- What we attend to
- Shifting our attention
- Joint and shared attention
- Competing attention
- Demands on attention

- Differences in attention

Sensory/Perceptual Differences

- The nature of the senses
- Touch, Taste, Vision, Auditory, Vestibular, Proprioceptive
- The Sensory Diet
- Equivalent behaviours and the senses

The author has noted that when delivering parent workshops in the past, an area which parents have expressed seeking additional support with, and sought greater understanding of, has been sensory processing issues, particularly as they can be related to ritualistic and obsessional behaviour which parents find hard to relate to and manage (Happe, 2005). It was felt important that parents would be able to link the learning between the two workshops and so workshop two made significant reference to the meaning behind behaviours linked to attention and sensory processing.

In considering the content of workshop two the author considered the abstractness of some of the learning. The learning was framed in the context of comparing typical attentional and sensory/perceptual processes with the observed behaviours in children with autism. Learning outcomes for parents included: understand that children with autism do not attend to things in a typical way and that the things which they attend to often seem atypical, understand that children with autism will have differences in how their attention shifts and how long they can attend to a task, understand that children with autism will have difficulty filtering out un-necessary information and sensory stimuli, understand that as human beings our brains make sense of the world by how we organise our senses, understand that depending on the importance of stimuli our brains will prioritise different sensory modalities, understand that pain is both a physical and psychological process, understand that children with autism experience sensory stimuli in an atypical way and that this will have implications for their behaviour, understand that by appreciating the sensory differences experienced by children with autism we can meet their sensory needs by creating a sensory diet that can be implemented in a naturalistic way.

The learning was to be supported by the use of video clips from you tube⁶, specifically these involved; a clip on the “McGurk Effect” (McGurk, and MacDonald, 1976), which demonstrates how the senses are organised and that one sensory modality will override the other relative to the meaning the sensory input has to the person; a clip on the “Rubber Hand Illusion” (Botvinick, and Cohen, 1998), which demonstrates how our senses are linked to our proprioceptive awareness, and a clip from the popular TV show “House” which showed how the pain experienced in “Phantom limb” is an illusion. The point of these illustrations was to show parents that the senses are a complex set of experiences and we should not ignore their role in influencing human behaviour. In addition, and to highlight how a sensory diet may work, a set of toys including squeeze balls, lights, bubble tubes, switches, chewy tubes were to be distributed amongst the parents and shown how they may be used to create a sensory diet. A fictitious child was to be discussed and a sensory diet developed given the child’s sensory needs and how these could be met.

6.3.3 Style of Workshop Delivery

Establishing therapeutic rapport has been noted in improving the knowledge and understanding of clinicians to the psychological distress of patients (Norfolk, Birdi and Patterson, 2009). In creating a context where parents felt they could express their experiences and feel listened to, the author felt it necessary that the workshops placed a focus on the establishment of trust between the professionals delivering the intervention and the participants, with the use of empathic listening and reflective skills being central in developing rapport and shared understanding. To facilitate the establishment of trust and disclosure within the parent workshop element of the intervention, it was decided that a set of rules would be a necessary part of the introduction to the workshop, specifying a need for respect of each others comments, confidentiality within the room, agreement not to disclose any of the discussions with any other party outwith the room without first seeking consent, an agreement that while one person is speaking others will listen and an understanding that no one person shall be judged on their views irrespective of that view conflicting with those held by another. The need for such rules would perhaps be particularly

⁶ You tube was chosen as it does not infringe copyright law and means that parents can watch again in their own time at home.

salient for workshops conducted in rural settings where it was understood that parents were more likely to come into contact with each other on a regular basis in both professional and social/leisure contexts.

It was envisaged that for the workshops to be effective, parents must feel they can share their thoughts and emotions regarding the challenges that raising a child with autism can bring. As such, it was felt that the Humanistic approaches with their emphasis on self disclosure (Jourard, 1974) offered the most appropriate delivery style to promote discussion amongst participants. Both Jourard (1969) and Rogers (1961) place significant emphasis on the establishment of therapeutic rapport by establishing a sense of equity between therapist and client. By adapting this approach workshops were to be delivered through the sharing of experience and providing illustration of behavioural management via scenarios of the presenter's/researcher's own experiences, highlighting both successes and failures with young people with autism. Moreover, by using experience as a vehicle to provide information, it was felt that parents would identify more readily with the learning material and reflect on their own situation and the challenges presented in caring for their son or daughter. By exploring parental experiences and by placing close attention to parental discussion, the delivery of the workshops would draw on early work within the realms of phenomenology and learning (Lewin, 1951), the workshops sought to engage participants in a dialogue regarding their experience of managing difficult and stressful situations with their son or daughter.

Given the meaning that parents derive from stressful situations involving their child it was considered that many of the parents experiences would have a highly emotive content. The benefit of humour in disrupting negative emotional states has been evidenced in a number of studies (Dillon, Minchoff, and Baker, 1985; Szabo, 2003; Abel, 2002) As such it was envisaged that the presenter/ researcher would use humour extensively in describing his own experiences of supporting children with autism to engage participants with the material, and also to assist understanding that some situations require an acceptance that behavioural change may not be possible. Given the discussion in earlier chapters, on low control/high stress situations, it was felt that parents were more likely to engage within the

workshop when it was demonstrated that highly regarded professionals make mistakes and accept that some challenging situations cannot be resolved.

6.3.4 Workshop Environment

Physical environments are important in establishing a therapeutic and informal forum in which to discuss sensitive, stressful and personal issues (Gesler, 1992). In taking consideration of the demands on parental time and the stress that travel may place on parents with demanding family and work lives, the workshops were to be delivered within each local authority area. As the researcher had limited knowledge of suitable venues within each of the three locality areas, the LA liaison person within each host local authority was asked to identify environments based on the following: a comfortable environment which was conducive to both presenting and discussing, an environment which provided opportunities for small break out areas where, during break periods, parents could have quiet conversations with one another or with family facilitators, an environment which provided lunch and tea/coffee in a separate area away from where the presentations were being given.

Identified venues and their resources were then discussed with the researcher before finalising for agreement. To maintain consistency and predictability, local authorities were asked to book the same venue for both workshops and funding was made available via the awarded Scottish Government grant to cover the costs of venue and subsistence. Aberdeenshire and Falkirk both provided hotels within their area which offered suitable accommodation, with Edinburgh City providing access to the Council Chambers and associated rooms with catering.

6.3.5 Development of Manuals

Both manuals (appendix 8, p.133) were designed as an adjunct to the learning of the workshops and as well as offering use as a centre piece of discussion with the family facilitators. The manuals were designed to deliberately reflect the content of both workshops, they developed the scenarios and case studies discussed within the workshops and provided an overall purpose of reframing parental experiences of challenging episodes. In so doing the aim of the manuals was to assist parents in

developing insight into their child's behaviour, offering practical advice and hopefully shifting beliefs from attempting to prevent all behaviours to accepting those that cannot be changed and identify ones which the parent feels more confident in addressing, as well as giving practical scenarios of how intervention may be constructed.

Both manuals made considerable use of appendices which could be used independently, and which could be photocopied by the parent. There was no expectation that the material must be used or that it should be used in a sequential way. Instead the aim of the manuals was to provide parents the option of dipping into materials at a pace that they were ready for. As such, the manuals were laid out in such a way that any section could be referred to at any given time.

To make the material as accessible as possible to parents a graphic designer was employed to illustrate the scenarios and concepts discussed and was consulted on layout and font size. Illustrations were included to support many of the case studies used to implement behaviour strategies and caution was used to ensure that the representation of the children was realistic, while not being overly dramatic. The examples provided in the manuals were based on the author's own experiences of directly supporting children with autism and the approaches he had found to work using the behavioural technologies and approaches discussed in the manuals.

The readability of the manuals was assessed and an average reading age was calculated using software available via micro-soft⁷, the index showed a readability rating of 63 placing the material in line with a reading age accessible to a typical 13 – 15 year old adolescent. However, it was noted that the reading skills required was higher in certain aspects of manual 1 where behavioural technologies such as behaviour recording were discussed. Where technical language was used the index highlighted that the skills required would be equivalent to those required to read the New York Times.

⁷ <http://office.microsoft.com/en-gb/word-help/test-your-document-s-readability->

6.3.6 *Family Facilitators*

The family facilitators were employed whilst the manuals were being developed and several weeks prior to the delivery of the first workshop. The choice of the name *Family Facilitators* was to reflect that their role was as a catalyst and agent of change within the family rather than to directly provide training or direction to parents on how to implement a prescriptive programme. Family Facilitators were seconded on a 0.5 basis from their existing posts within the National Autistic Society, and their salaries and expenses were covered from the Scottish Government grant provided to fund the study. The author placed an advert in the National Autistic Society's internal posts circular, and interviews were held for the posts during the programme's development phase. Four facilitators were employed⁸, 2 had psychology degrees and were working as assistant psychologists, another had qualifications in nursery school teaching and was currently working as a classroom assistant, and the third was a deputy head teacher with teaching qualifications and additional postgraduate training in additional support needs. This last member of the team also contributed to the writing of the second manual. . Selection of facilitators was based on a number of factors which included; good interpersonal skills, good communication skills, both orally and written, experience of working with children with autism who can exhibit challenging behaviour, a basic understanding of the behavioural technologies employed in the study, and empathy and life experience. In addition, facilitators needed to demonstrate that they had the capacity to listen without judging and they were all required to provide examples of this during their interviews.

The programme was designed to provide twenty-one hours of Family Facilitator support. However, this was not required to always be delivered by face-to-face contact, except on the first meeting with parents which would be at a place of the parent's choosing but was envisaged that it would generally take place at the parents home. After the initial meeting subsequent meetings could be by email, telephone or other electronic means, as the sessions could be used in whichever way was most beneficial to the family in terms of time and medium and would be based on the preference of the parent/s. In addition, parents were informed that there were

⁸ This was from a group of 21 applicants

no prescribed times of day or time limits set on sessions, but simply that there was an overall time allocation of 21 hours. The twenty-one hours of Facilitator time did not include travel time and it was envisaged that due to the distances involved with some of the Aberdeenshire families that some overnight stays may be required. As the development phase of the programme was during the late autumn of 2008, it was envisaged that the first visits to the Aberdeenshire families would not be until March of 2009, which would hopefully ensure improved weather and light for travelling.

In addition to the twenty-one hours of direct facilitator time with the families, facilitators were also expected to engage in other duties connected with the programme. These included commentaries of contact and the support provided⁹, the organisation associated with the delivery of each workshop (e.g. ensuring that all parents were notified and familiar with the venue, and that catering had been accommodated for), entering information into the computer allocated to the programme, management and recording of allocated monies to carry out their roles.

6.3.7 Family Facilitator Induction and Supervision

Following recruitment the Family Facilitators were given four days of induction training. The first two days focused on the Parent Programme the rationale for its development, the workshops and the manuals as well as all organisational aspects associated with the programme and their role in its delivery and management. The remaining two days were used to introduce the Facilitators to the concepts and techniques of Motivational Interviewing as well as working alongside them to set up the administrative systems required for the running and evaluation of the programme. While two of the Facilitators were Psychology graduates, none of the four had any previous training in MI or were aware of how it is used clinically. Rather than provide them with a history and background to MI, it was felt that a more practical use of the time was to directly engage with the “spirit” of the approach the techniques employed, and the psychological constructs of motivation and ambivalence. The two days were designed to use both formal teaching via power point handouts and practical sessions where the facilitators would practice skills on one another lead by the researcher and informed by the power point

⁹ These were notes for supervision which allowed the researcher to monitor how the Facilitators interacted with parents

handouts. In addition, it was planned that throughout the intervention the four Family Facilitators would receive both group and individual supervision from the author, on a basis of 1 hour supervision for every 3 hours of family work, with the author being available at any time should additional support be required. Supervision sessions would be used to discuss individual families, where facilitators may be “getting stuck” and fine-tune motivational interviewing skills.

The approach adopted in this parents programme takes consideration of how individual family members appraise the behaviour of their son/daughter and cope with the resulting stressor. However, as indicated in earlier chapters, many families report a sense of isolation that can in part be a function of hopelessness, derived from past experiences of being unable to change their child’s behaviour (Jones, 1997; Powers, 1989; Tommasone and Tommasone, 1989). It was envisaged that Family Facilitators would confront this within their work with families and that parents may simply request that Family Facilitators provide direction on how to resolve behavioural issues. Given the lack of experience of using MI and the background and experiences of the Family Facilitators as professionals who are involved in the delivery of care and education to children with autism, it was envisaged that the area of MI that they would struggle most with was the ability to resist the “righting reflex”. The righting reflex refers to a tendency to ensure that the parent understands and agrees with the need to change and to find solutions for the parent. While the righting reflex is born out of concern for the parent and the situation they find themselves in, it prevents the parent from dealing with their own issues of ambivalence, self-efficacy and confidence. To guard against this, considerable time was built into the induction programme focussing on when and how this may arise, with Family Facilitators engaging in role play to practice how they would address this issue.

As autism does not fit neatly into mental health or learning disability frameworks there is a risk that families could previously have been offered advice that does not fit with their experience of their child. It is noted in the literature that when families have received advice from professionals that has either been misguided or inappropriate, they are less likely to adopt new strategies or trust in approaches developed by professionals that require commitment and resource

(Sharpley, Bitsika and Efremidis, 1997). Thus, it was anticipated that Family Facilitators may experience resistance to their role due to parental experience of past failure resulting from a lack of appropriate training and/or understanding, from the professionals providing that advice. To help address this issue the induction was designed to allow Family Facilitators to role-play resistance from parents. MI skills of rolling with resistance could then be practiced while not losing sight of allowing parents to address behavioural issues.

During this induction phase, and prior to the delivery of the first workshops¹⁰ Family Facilitators practiced the skills necessary to direct parents to the appropriate elements of the manuals that could be used as a focal point to discuss feelings of ambivalence, this was achieved through the practicing of open ended questions, reflecting and summarising. For example, facilitators would practice conversational pieces such as “What you have described sounds like what the manual tells us about sensory issues, what aspects of that do you see in your child?” Moreover, it was important that Family Facilitators blended the skills necessary to practice MI with the material in the manual and become familiar and confident with their role. Scenarios were developed with the Family Facilitators during their induction where they could practice the skills necessary to support parents develop behavioural supports for their son/daughter and be supported in identifying appropriate target behaviours. To facilitate this Family Facilitators practiced using the importance/confidence ruler (Butler *et al.*, 1999; Rollnick, Mason and Butler, 1999) as it was laid out in the manual. It was hoped that in developing this skill Family Facilitators would become proficient in supporting parents to identify behaviours that they could address and succeed in making a change. By asking parents to rate both the importance of a specific behaviour and their confidence in being able to implement change relative to it, it was hoped that Family Facilitators would assist parents in choosing behaviours that they were more likely to succeed with which in turn would develop parent confidence in behaviour change.

¹⁰

Family Facilitators attended all workshops, providing administrative support and joining in on the discussion pieces with parents and the researcher. Prior to the first workshop parents were assigned a Family Facilitator and the first workshop was used as an opportunity to make introductions

6.3.8 Timescales for the Development, Delivery and Evaluation of the Parent Programme

Oct – Dec 2008	Development of programme materials (Workshops and Manuals), Recruitment and induction of Family Facilitators
Feb –March 2009	Delivery of Workshop 1 in Local Authority areas
March- June 2009	Family Facilitators Meet with Families No Activity due to summer holidays
Aug-Sep 2009	Delivery of Workshop 2 in Local Authority areas
Sep-Oct 2009	Family Facilitators meet with families
Nov 2009	Evaluation of Parent Programme

6.4 Outcome Measures

6.4.1 The Parenting Stress Index-Short Form 3rd Edition (PSI-LF) (Abidin 1995)

The term 'parenting stress' encompasses the difficulties in adjusting to the parenting role. The Parenting Stress Index (PSI) examines the level of stress within the parent-child system and consists of factors reflecting a parental domain of coping and perceptions of the child. Within the parent domain the subscales assess a range of factors including depression, maternal health, difficult child and difficult parent-child interaction.

The tool is a 120-item questionnaire with statements on a five-point Likert scale. The items for the two domains use a five-point Likert scale ranging from “strongly agree” to “strongly disagree” to assess parents’ opinions. The first domain is the Child Characteristics domain, which includes the subscales Adaptability, Demandingness, Mood, Distractibility/Hyperactivity, Acceptability of Child to Parent, and Child’s Reinforcement of Parent (Abidin, 1997; Loyd and Abidin, 1985). When scores are elevated in this domain it is associated with children whose behaviour causes significant stress to their parents and makes it difficult for them to fulfil their parenting role (Loyd and Abidin, 1985). The second domain is the Parent Characteristics domain, which includes the subscales Depression, Attachment to Child, Social Isolation, Sense of Competence in the Parenting Role, Relationship with Spouse/Parenting Partner, Role Restrictions, and Parental Health (Abidin, 1997;

Loyd and Abidin, 1985). A Total Stress score is obtained by adding the two domain scores. The Stressful Life Events Scale is a yes/no item format evaluating the major life events that occurred for the parent within the last year (Abidin, 1997). With these domains, it is clear that both parent and child characteristics are viewed as important dimensions of parenting stress. Also, with the addition of the Stressful Life Events Scale, the daily hassles and the related adjustment are also considered. The test-retest reliability for the Total Stress score on the Parent Stress Index ranges from .88-.90 and the test's concurrent validity has been established with a number of measures, including the Beck Depression Inventory, Child Abuse Potential Inventory, Child Behavior Scale, Eyeberg Child Behavior Inventory, Family Adaptability and Cohesion Evaluation Scales, and Family Impact Questionnaire. The two broadband scores-child domain stress and parent domain stress were used for this study.

6.4.2 The Ways of Coping Scale

To determine which coping styles participants generally used, The Ways of Coping (Revised) was administered (Folkman and Lazarus, 1985). This measure contains 67 items divided into 8 domains (1. Confrontive coping, 2. Distancing, 3. Self-controlling, 4. Seeking social support, 5. Accepting responsibility, 6. Escape-avoidance, 7. Planful problem-solving, 8. Positive reappraisal) these describe a broad range of cognitive and behavioural strategies people use to manage internal and/or external demands in specific stressful encounters. The scale is a 4-point Likert scale (0 = *does not apply and/ or not used*; 1 = *used somewhat*; 2 = *used quite a bit*; 3 = *used a great deal*), derived from the theoretical model of stress and coping postulated by Lazarus, Folkman and other researchers. In developing the scale the authors examined the interaction between appraisal and coping, and the outcomes of a stressful encounter (Folkman *et al.*, 1986). The theoretical model on which the measure of coping is developed examines the relationship between stress appraisal and coping style and acknowledges the role of primary and secondary cognitions during a stressful encounter. As outlined previously the intervention described within this thesis utilises knowledge of this relationship to influence parent appraisals. Rather than “treating” behaviour the intervention aims to influence appraisals by developing parental understanding of their child’s behaviour and

assisting in parents in their appraisals of what behaviours may be influenced by social valid approaches to management.

The eight domains described above have coefficients of internal consistency ranging from 0.61 to 0.79. Coefficients of reliability (Cronbach's alpha) are displayed in table 5 below (Folkman et al. 1986)

Scale	No of Items	Alpha
Chronbach's		
Confrontive Coping	6	0.70
Distancing	6	0.61
Self-Controlling	7	0.70
Seeking Social Support	6	0.76
Accepting Responsibility	4	0.66
Escape Avoidance	8	0.72
Planful Problem Solving	6	0.68
Positive Reappraisal		

Table 5 WC-R scales, items and reliability coefficients

6.4.3 Completion of Questionnaires

Questionnaires were distributed and completed at three time intervals during the Parent Programme. Once participants had assembled to take part in *Workshop 1* and introductions had been made, the researcher distributed questionnaires for completion and gave verbal instruction as to how they should be completed. Once all questionnaires had been completed they were then collected and the Workshop was delivered. This process was repeated when participants assembled for *Workshop 2* and finally Questionnaires were completed at the end of the last visit made by Family Facilitators which all occurred after *Workshop 2*.

It was envisaged that this would be the most reliable way by which to ensure 100% return on the questionnaires and the controlled environment in which they were carried out ensured authenticity of the responses and enabled the researcher to assist with any questions regarding their completion.

6.5 Data Analyses

The study took measures over three time intervals with an overall aim to evaluate the impact of the Parent Programme on reducing parent stress. As such the aim, research questions and design of the study influenced the choice of analyses.

Data analysis was conducted using SPSS version 19 for repeated measures ANOVA, which compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The analysis aimed to explore changes in stress variables as moderated by the Parent Programme. In addition, the analysis explored changes in the use of certain coping styles as described in the transactional model of stress and coping (Lazarus and Folkman, 1984). Prior to applying the analysis checks were made on the data for normality and kurtosis. Post hoc checks were also applied to check for both type 1 and type 2 errors.

Chapter Seven

Results

This chapter details the results of the study. The study tested three hypotheses:

Hypothesis 1. It was predicted that parental stress related to child characteristics would reduce resulting from the intervention.

Hypothesis 2. It was predicted that parental stress related to parent characteristics would reduce resulting from the intervention.

Hypothesis 3. It was predicted that parental coping styles would change as the intervention allows parents to explore their own coping resources when considering behavioural change.

The hypotheses were tested using the Parenting Stress Index (Abidin, 1995) and changes in coping variables explored using the *transactional* model of stress and coping (Lazarus and Folkman, 1984). Descriptive statistics are presented according to the measures used followed by analysis of the relations between the independent and dependent variables using a repeated measures ANOVA¹¹, within the general linear model. Repeated measures ANOVA has been found to be a reliable tool to analyse data where the aim of the study is to determine whether or not change has occurred over time (Chi and Reinsel, 1989), it achieves this by comparing the average score at multiple time periods for a single group of subjects, as was performed within this study.

Questionnaires were analysed for the 71 participants on the results obtained for the Parenting Stress Index (PSI-LF) and Ways of Coping-Revised (WoC-R). The current sample size N=71 compares favourably with other studies in the area of autism and parent intervention, many published studies have relatively low sample sizes and the number included in this study is higher than that generally reported (Diggle and McConnachie, 2009). This has been a general criticism of studies in this

¹¹ Although not a hypothesis of the study, paired sample t-tests were carried out on the data for each LA separately. This was to provide feedback to each LA based on their own population

area and a number of researchers have highlighted the risk of bias due to the lack of representative samples (Diggle and McConnachie, 2009; Fombonne, 2001) attributing small sample sizes to the low prevalence rate of autism in the community.

7.1 Assessing Normality and Post Hoc tests

The repeated measures design assumes that the dependent variables are normally distributed. To test for this, skewness and kurtosis was assessed for all dependent variables in the study. To satisfy the assumption of normality the boundaries for both skewness and kurtosis, was set at +2.0 and -2.0 (De Carlo, 1997). Furthermore, in repeated measures ANOVA, the same subjects are used at each time period, so there is an expectation that the measures will be correlated across subjects, if the correlations across time periods are similar (sphericity). If they are not similar, such as they are getting stronger over time, this will make the differences between time periods stronger than they really are. If sphericity is violated, the computed significance for the F-tests are too low and we may be rejecting the null hypothesis when we shouldn't (type 1 error). To assess this Mauchly's test of sphericity was employed within the analysis. Post hoc tests using Bonferroni correction were applied to increase the degrees of freedom for the test, which in turn reduces the significance level to a more accurate number.

7.2. Parenting Stress Index Results (n=71)

7.2.1 Hypothesis 1

In order to test the hypothesis that parental stress scores associated with child characteristics and measured by the Child Domain of the PSI prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. To check for compliance with sample size requirements, univariate general linear model procedures were conducted. The minimum sample size requirement that was within the repeated measures ANOVA was $10 + \text{the number of dependent variables}$ (Tabachnick and Fidell, 2007). As the number of cases was 71 and the number of dependent variables in the analysis was 3 (time periods, assessed) the resulting number is 74 which satisfies the minimum sample size requirement (13). At time 1 the Skewness of the distribution was .586 and the Kurtosis was -.242,

as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 2 the Skewness of the distribution was .420 and the Kurtosis was -.660, as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was .726 and the Kurtosis was -.310, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The means and standard deviations are presented in table 6 below. There was a significant effect for time, Wilks' Lambda = .103, $F(2, 69) = 299.317$, $p < .0005$, multivariate eta squared = .897

Table 6. Descriptive Statistics for parental stress associated with child characteristics

Time Period	N	Mean	Standard Deviation
Time 1	71	151.63	22.816
Time 2	71	111.75	19.739
Time 3	71	97.55	9.892

The results presented above indicate a significant change with a large effect size in parenting stress associated with child characteristics. The results suggest a significant reduction in stress for those parents participating in the family programme whose stress arose from their view of their child's behaviour. This overall reduction in stress associated with child characteristics was relatively large, with the greatest reduction being prior to the intervention to a midpoint half way through the programme. A further reduction in stress was experienced at the end of the intervention but was not to the same scale as was first observed.

The probability of Mauchly's test for sphericity was .849 with $p = .004$, therefore as $p < 0.05$ the assumption of sphericity was not satisfied. Greenhouse-Geisser, corrects for violations of the assumption of sphericity as it is a more conservative estimate, $\epsilon = .869$. When $\epsilon > .75$ there is a risk of rejecting the null hypothesis that sphericity holds (Collier, Baker, Mandeville and Hayes, 1967). Therefore the Huynh-Feldt correction (Girden, 1992) was applied. Here $\epsilon = 1.00$,

1.00(1.0)= 1 lower bound, 1.00(140) = 140 upper bound, therefore the assumption of sphericity is met.

Post Hoc Tests

Huynh-Feldt correction determined that mean parental stress associated with child characteristics differed statistically significantly between time points $F(2.000, 140) = 337.056, p < 0.0005$. The post hoc tests using Bonferroni correction revealed that the parent programme was effective in reducing parent stress associated with child characteristics prior to intervention (time1)($M=151.63, SD= 22.816$) to a mid point in the intervention(time 2) ($M= 111.75, SD=19.739$), which was statistically significant $p<0.0005$. Furthermore, the intervention maintained this reduction in stress (though not to the same degree) till the end of the programme (time 3) ($M=97.55, SD=9.892$). This further reduction was also statistically significant $p<0.0005$. We can therefore confirm that the Parent Programme gave rise to reductions in stress experienced by participating parents of children with autism that are associated with child characteristics such as behaviour which is symptomatic of autism.

7.2.2 Hypothesis 2

In order to test the hypothesis that parental stress scores associated with parent characteristics and measured by the Parent Domain of the PSI prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. To check for compliance with sample size requirements, univariate general linear model procedures were conducted. As above, the minimum sample size requirement that was within the repeated measures ANOVA was 10 + the number of dependent variables (Tabachnick and Fidell, 2007). As before the number of cases was 71 and the number of dependent variables in the analysis was 3 (time periods, assessed) the resulting number is 74 which satisfies the minimum sample size requirement (13). At time 1 the Skewness of the distribution was .49 and the Kurtosis was -.973, as both values fall between +2.0 and -2.0 the assumption

of normality was upheld. At time 2 the Skewness of the distribution was .944 and the Kurtosis was 1.343, as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was .763 and the Kurtosis was .563, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The probability of Mauchly's test for sphericity was .987 with $p = .635$, therefore as $p > 0.05$ the assumption of sphericity was satisfied. The ANOVA compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The means and standard deviations are presented in table 6 below. There was a significant effect for time, Wilks' Lambda = .174, $F(2, 69) = 164.173$, $p < .0005$, multivariate eta squared = .826

Table 7 Descriptive Statistics for parental stress associated with parental characteristics

Time Period	N	Mean	Standard Deviation
Time 1	71	146.87	27.741
Time 2	71	111.10	20.399
Time 3	71	98.39	11.098

The results indicate a significant change with a large effect size in parenting stress associated with parental characteristics. The results suggest a significant reduction in stress for those parents participating in the family programme whose stress arose from parent stressors associated with child behaviour, such as depression and isolation. This overall reduction in stress associated with parent characteristics was relatively large, with the greatest reduction being prior to the intervention to a midpoint half way through the programme. A further reduction in stress was experienced at the end of the intervention but was not to the same scale as was first observed.

Post Hoc Tests

Bonferroni correction determined that mean parental stress associated with parent characteristics differed statistically significantly between time points $F(2.000, 140) = 226.873, p < 0.0005$. The post hoc tests using Bonferroni correction revealed that the parent programme was effective in reducing parent stress associated with parent characteristics prior to intervention (time1)($M=146.87, SD= 27.741$) to a mid point in the intervention (time 2) ($M= 111.10, SD=20.399$) which was statistically significant $p<0.0005$. Furthermore, the intervention maintained this reduction in stress (though not to the same degree) till the end of the programme (time 3) ($M=98.39, SD=11.098$). This further reduction was also statistically significant $p<0.0005$. We can therefore conclude that the Parent Programme gives rise to reductions in stress experienced by parents of children with autism that are associated with parent characteristics.

7.3 Hypothesis 3

Ways of Coping Results (n=71)

The *transactional* model of stress (Folkman and Lazarus, 1984) explores the relationship between the stress response and the coping styles used by the individual. Hypothesis 3 of the study predicted changes in coping variables as parents interacted with the Parent Programme. Specifically, the study aimed to explore changes in *accepting responsibility, confrontive coping, self controlling and positive re-appraisal*, a set of coping styles which may reflect changes in parental beliefs as to the degree to which child behaviours may change (Aldwin *et al.*, 1980, Lazarus, 1986) and offer healthier psychological outcomes.

Although analysis was carried out on all three time points in the coping domains explored, the analyses of variables was primarily concerned with investigating the hypotheses that the intervention would result in a change in the use of coping styles, with the two time intervals, time 1 and time 3 being of the greatest interest. Sphericity is always met for two levels of a repeated measure, and therefore given that the main focust was change in coping styles from the beginning to the end of the intervention, sphericity is met.

Sample size requirements, and normality was assessed for coping dependent variables. The minimum sample size requirement that was within the repeated measures ANOVA was $10 +$ the number of dependent variables, which was 2 as only two time periods were being compared. As the number of cases was 71 and the number of dependent variables in the analysis was 2 (time periods, assessed) the resulting number is 73 which satisfies the minimum sample size requirement (12) across all of the coping variables evaluated.

7.3.1 *Accepting Responsibility*

In order to test the hypothesis that total *accepting responsibility* prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. At time 1 the Skewness of the distribution was .328 and the Kurtosis was -.490 as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was -.355 and the Kurtosis was -.326, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The ANOVA compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The means and standard deviations are presented in table 8 below. There was a significant effect for time, Wilks' Lambda =.526, $F(2, 69)= 31.052$, $p<.0005$, multivariate eta squared =.474

Table 8. Descriptive Statistics for accepting responsibility

Time Period	N	Mean	Standard Deviation
Time 1	71	5.20	2.214
Time 2	71	8.10	3.190
Time 3	71	8.15	3.115

The results indicate a significant change in the use of the coping style *accepting responsibility* with a large effect size. Bonferroni correction determined that the mean use of *accepting responsibility* differed statistically significantly between time points $F(1, 70) = 61.859, p < 0.0005$. The post hoc tests using bonferroni correction revealed that the parent programme was effective in increasing the use of accepting responsibility from a time point prior to intervention (time1)($M=5.20, SD= 2.214$) to the end of the programme (time 3) ($M=8.15, SD=3.115$) which was statistically significant $p<0.0005$. We can therefore conclude that the Parent Programme gave rise to an increased use of accepting responsibility as a coping style in those participating in the programme

7.3.2 Confrontive Coping

In order to test the hypothesis that total *confrontive coping* prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. At time 1 the Skewness of the distribution was -.260 and the Kurtosis was -.796 as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was -.191 and the Kurtosis was -.677, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The ANOVA compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The means and standard deviations are presented in table 9 below. There was a significant effect for time, Wilks' Lambda =.710, $F(2, 69) = 14.112, p<.0005$, multivariate eta squared =.290

Table 9 Descriptive Statistics for confrontive coping

Time Period	N	Mean	Standard Deviation
Time 1	71	6.48	2.222
Time 2	71	8.18	2.820
Time 3	71	8.28	2.663

The results indicate a significant change with a large effect size in the use of the coping style *confrontive coping*. Bonferroni correction determined that the mean use of *confrontive coping* differed statistically significantly between time points $F(1, 70) = 28.578, p < 0.0005$. The post hoc tests using bonferroni correction revealed that the parent programme was effective in increasing the use of *confrontive coping* from a time point prior to intervention (time1)($M=6.48, SD= 2.222$) to the end of the programme (time 3) ($M=8.28, SD=2.663$) which was statistically significant $p<0.0005$. We can therefore conclude that the Parent Programme gives rise to an increased use of *confrontive coping* as a coping style.

7.3.3 Self Controlling

In order to test the hypothesis that total *self controlling* prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. At time 1 the Skewness of the distribution was .001 and the Kurtosis was .066 as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was -.498 and the Kurtosis was .285, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The ANOVA compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The means and standard deviations are presented in table 10 (p.93). There was a significant effect for time, Wilks' Lambda =.645, $F(2, 69) = 19.010, p<.0005$, multivariate eta squared =.355

Table 10. Descriptive Statistics for self-controlling

Time Period	N	Mean	Standard Deviation
Time 1	71	9.08	3.363
Time 2	71	9.75	3.600
Time 3	71	8.85	3.197

The results indicate a significant change with a large effect size in the use of the coping style *self controlling*. Bonferroni correction determined that the mean use of *self controlling* did not differ statistically significantly between time points, $F(1, 70) = .447, p = .506$. Therefore the parent programme did not alter the use of the coping style *self controlling*.

7.3.4 Positive Re-appraisal

In order to test the hypothesis that total *positive re-appraisal* prior to and following the intervention would be significantly different a repeated measures ANOVA was performed. At time 1 the Skewness of the distribution was .292 and the Kurtosis was -.424 as both values fall between +2.0 and -2.0 the assumption of normality was upheld. At time 3 the Skewness of the distribution was -.738 and the Kurtosis was .354, as both values fall between +2.0 and -2.0 the assumption of normality was upheld.

The ANOVA compared scores at Time 1 (prior to intervention), Time 2 (at a midpoint, prior to workshop 2), and at Time 3 at the end of the intervention. The means and standard deviations are presented in table 11 below. There was a significant effect for time, Wilks' Lambda = .350, $F(2, 69) = 63.169, p < .0005$, multivariate eta squared = .650.

Table 11 Descriptive Statistics for Positive Re-appraisal

Time Period	N	Mean	Standard Deviation
Time 1	71	7.94	3.468
Time 2	71	11.53	4.003
Time 3	71	12.64	3.017

The results indicate a significant change in the use of the coping style *positive reappraisal*, with a large effect size. However, Bonferroni correction determined that the mean use of *positive re-appraisal* did not differ statistically significantly

between time points, $F(1, 69) = .172, p = .679$, therefore the parent programme did not alter the use of the coping style *positive re-appraisal*.

7.4 PSI Sub-Domains

The PSI comprises two domains, the Child Domain and the Parent Domain. The Child domain is divided into the following sub-domains; Adaptability, Acceptability, Demandingness, Mood, Distractibility/Hyperactivity and Reinforces Parent. The Parent Domain is divided into the following sub-domains; Depression, Attachment, Role Restriction, Sense of Competence, Social Isolation, Relationship with Spouse and Parent Health. Descriptive statistics for the sub-domains are outlined in Appendix 9 (P.134)

Within the Child Domain the greatest difference in means from time 1 (prior to intervention) to time 2 (mid-point within intervention) was within the sub-domain *Adaptability*. This was also the case for the difference between time 2 and time 3 (end of intervention), as well as the difference between time 1 and time 3. The smallest difference between all time comparisons in the Child Domain was observed in the sub-domain *Mood*.

Within the Parent Domain the greatest difference in means from time 1 (prior to intervention) to time 2 (mid-point within intervention) was within the sub-domain *Competence*. This was also the case for the difference between time 2 and time 3 (end of intervention), as well as the difference between time 1 and time 3. With the exception of *Spouse* as measured between time 2 and time 3, the smallest difference between all time comparisons in the Child Domain was observed in the sub-domain *Health*.

7.5 Clinical Changes

At time 1 within the Child Domain of the PSI, the clinical cut offs' showed that 94% (n=67) of the parents were in the clinical range of stress associated with child characteristics while only 6% (n=4) were subclinical. At time 2 this figure had changed significantly to 24% (n=17) being within the clinical range and 76% (n=54) being sub-clinical. By the end of the intervention there was a further reduction to 8% (n=6) clinical range and 92% (n=65) for sub-clinical. While the study showed a

statistically significant reduction in parental stress associated with parenting characteristics the degree of clinical difference was not as profound as that shown by the Child Domain scores. At time 1, 48% (n=34) were clinically stressed, while 52% were in the sub-clinical range. This is in stark contrast to the experience of stress within the child domain, which was much higher. This picture continued through the other time periods. At time 2 these figures had changed to 10% clinical (n=7) and 90% (n=64), with a further change in numbers by the end of the intervention to 0% (n=0) clinical, 100% (n=71) sub-clinical.

7.5.1 Correlations

Correlation analysis was conducted to explore the relationships and associations between coping variables and stress measured within the PSI. A Pearson product-moment correlation was carried out on the data set yielding a large number of associations (appendix 10). However, the only one association was observed in two time periods. At time 1 there was a medium negative association between planful problem solving and parent health within the PSI $r=-.417$, $p<0.01$. While no association was detected at time 2, a small negative relationship was detected at time 3, $r=-.263$, $p<0.05$. Indicating that planful problem solving is associated with poorer health in parents.

Tests for normality identified a number of variables in the data set that were significant, indicating that suggesting a violation of the assumption of normality. As the distribution of the data may be misleading a further analysis using Spearman's rank correlation was carried out as it does not require a linear relationship between variables. However, Spearman's did not identify the same relationship between planful problem solving and parent health. Rather two separate associations were identified. At time 2 confrontive coping had a negative medium relationship with parent competence, $r_s=-.310$, $p<0.01$, which carried on into a small relationship at time 3, $r_s=-.290$, $p<0.05$, indicating that parents using confrontive coping midway through the intervention felt less competent within their parenting skills. Similarly, at time 2 a small negative relationship was found between planful problem solving

and parent competence, $r_s = -.261$ $p < 0.05$, which was also present at time 3, $r_s = -.271$, $p < 0.05$. Indicating that use of planful problem solving as a coping style is associated with parents feeling less competent.

Both planful problem solving and confrontive coping are associated with problem focussed coping styles. While the Spearman's correlation analysis indicated that parent competence was reduced by use of coping styles that were more problem focussed it is difficult to assert that there is a causal relationship between this type of coping style and parent appraisal of poor competence. Analysis such as cross-legged correlations can provide information regarding causal direction. However, given the absence of a theoretical basis for associations between PSI and Ways of Coping and the number of variables within the PSI, results of such an analysis would be highly spurious. Nevertheless, this does raise important questions for future research. The current study explored changes in parental stress as a result of using the psycho-educational approach described, however, further exploration should be conducted to investigate the theoretical associations between parental stress subdomains and coping styles. Such investigation would perhaps offer greater insight into the relationship between stress and coping.

7.6 Central Findings

The results demonstrate that for the cohort of 71 parents who engaged with this intervention there was a significant reduction in parental stress associated with both child and parent characteristics. This was a reduction that was maintained throughout the intervention and was also associated by significant changes in the clinical presentation of parents. In addition, the results suggest that the intervention had the greatest effect on parental views of their child's *adaptability*, and that this construct predicted the greatest reduction in stress associated with child characteristics. The construct of perceived *competence* changed the most within the parent domain, and the results suggest that this had the greatest predictive value in determining reductions in parental stress as a result of the intervention. Reductions in parental stress were also associated with an increased use of the coping styles *accepting responsibility* and *confrontive coping*. These styles reflect both emotion

and problem focussed coping approaches and suggest that both these approaches to coping are employed by parents of children with autism.

The pattern of sharp reduction in stress experienced from time 1 to time 2 and then the further statistically significant but not as dramatic reduction from time 2 to time 3 is consistent with most studies in general, where ANOVA has been used as a statistical technique and intervention has shown to have a significant effect (Keselman, Algina and Kowaluchuk, 2001). The relationship between independent and dependent variables seems to have greatest effect at the initial stage of intervention, subsequent changes tend to have more of a maintenance effect and therefore tend to be less dramatic.

Chapter 8

Discussion and Conclusion

Unlike other parent-mediated interventions, this study focused exclusively on parents rather than the child with autism. The results show reduced stress in both the child and parent domains of the PSI implying that some form of cognitive process had occurred for parents during the intervention. The standard approach to intervention in parents is to train them in the delivery of a specific programme that will address skill deficits within the child such as communication or academic performance (Diggle and McConnachie, 2009). However, this intervention simply addressed the cognitions held by parents regarding their child's behaviour, and the beliefs regarding what behaviours they could address given their internal resources.

As discussed earlier in this thesis, appraisals are cognitive processes which involve the evaluation of events to determine their relevance to the individual, and whether the individual has the resources to avoid or prevent harm by altering the situation in some way (Folkman *et al.*, 1986). It would seem that by developing parental understanding of their child's behaviour and providing the means by which parents can reflect upon their ability not to eliminate but rather shape behaviour into socially valid expression we can reduce parent stress. As individuals understand the nature of stressful encounters then they are more able to generate possible strategies to manage the stress they experience (Billings and Moos, 1981; Folkman, 1984). Here the derivation of *meaning* is crucial in how people make *appraisals* of the stressor. In managing their child's behaviour during stressful episodes, if parents are able to derive meaning, from their child's behaviour then it allows them to generate strategies on how to respond. The workshops and manuals provide extensive information as to the meaning behind some of the odd or challenging behaviour that children with autism may present with. Lazarus (1991) asserts that when individuals relate the meaning behind stressful events and how this relates to their own interpretation of the event, the individual's emotional response alters. By assisting parental understanding of child behaviour, the relationship between the meaning behind the child's behaviour and the parents' emotional response will likewise change, with knowledge mediating within this change.

8.1 Adaptability

The very crux of the intervention described in this thesis is the alteration of parent appraisals of their child's behaviour and of their own appraisals of their role as parents. When we examine the change in means within the PSI sub-domains we observe that the greatest change within the child domain is within the construct of *adaptability*. Abidin (1995) describes this construct as relating to behavioural characteristics that make the child very difficult to manage. Specifically, the child is lacking in adaptability and plasticity resulting in overreaction to changes in routine and problems in establishing schedules, followed by perseveration in behaviour. In addition, Abidin (1995) notes that parents who rate their child high in this sub-domain also view them as having problems in adjusting to strangers and resistant to the calming or soothing efforts of the parent. Rigidity of behaviour, a requirement for sameness, fear of strangers and an inability to regulate emotion are behaviours' that are commonly found in children with autism (McClintock, Hall and Oliver, 2003). Moreover, as Hastings *et al.* (2005) points out such behaviours are often considered socially inappropriate and are central to the stress experienced by parents of children with autism. Many approaches such as ABA, Son-Rise and Floortime, instruct parents in techniques to intensively apply to their child with the aim of eliminating such behaviours (Howlin, Magiati and Charman, 2009; McConachie and Diggle, 2007). By comparison, no such skill was taught within the parent programme and no direction was given to parents as to how to eliminate these behaviours within their child. However, these behaviours were discussed in both the workshops and the manuals, and many illustrations were provided as to how these behaviours provide an insight into how a child with autism experiences the world. Moreover, the Positive Programming approach outlined in the parent programme teaches us that in understanding the meaning behind these behaviours we can offer children with autism supports to manage these behaviours within socially inclusive environments.

When we consider the components of the parent programme concerned with the sets of behaviour which *adaptability* within the PSI measures we observe elements of both emotion and problem-focussed coping. The development of knowledge as to how a behaviour arises in a child with autism allows us to appraise

whether there is any aspect of that behaviour that we can influence or whether we simply must accept the situation, remain calm and keep that person and ourselves safe from harm. As a result of the intervention parents increased their use of the coping style *accepting responsibility*. This is primarily an emotion focussed coping style (Folkman and Lazarus, 1988), which is highly correlated with positive re-appraisal (Folkman and Lazarus, 1985). The construct of *accepting responsibility* is aligned with appraisals regarding our role within the stressful encounter (Lazarus, 1991). Where children with autism are presenting in a rigid, fearful and stereotypical manner, it is important for the carer to reflect if there is any action that they may have done that has contributed to the behaviour and if by altering their own behaviour they can reduce the stress experienced by the child. Both workshops and manuals touch on this area. In workshop and manual 1, consideration is given to the role of carer in their interpretation and maintenance of challenging behaviour. Page 18 of Manual 1 describes the limited *Opportunities for Interaction* that many children with autism experience and illustrates that behaviour that may seem socially inappropriate such as “hitting” may in fact be a means of engaging for a child with autism. This interpretation requires a re-appraisal of what would normally be deemed as a challenging situation. It requires the parent to reflect on the situation and accept their role in setting up opportunities for play with other children that may be overwhelming to the child with autism if they do not understand the rules involved.

The use of *Confrontive coping* was also noted to increase as a result of the intervention. This problem-focussed coping style is associated with meeting problems “head-on” rather than using avoidant styles of coping. It is also associated with efforts to aggressively alter the situation and suggests some degree of risk-taking (Folkman and Lazarus, 1980). As parents experience less stress relating to their child’s lack of *adaptability* their confidence will no doubt grow. While there was no measure of confidence within the intervention, the transactional model of stress indicates that coping may influence a person’s re-appraisal (Folkman *et al.*, 1986). The re-appraisal may be viewed as a means of experiencing the encounter as less stressful and increasing parent confidence to *confront* every-day events that they would previously have avoided due to the fear of threat for the safety of their child or

from the views of others within the community. Taking action such as having renewed confidence to enter public settings which previously a parent would have avoided for fear of their child's behaviour, is a form of *confrontive coping*, as it is congruent with meeting the encounter "head-on" and can be seen as the opposite of avoidant or escape based coping styles.

8.2 Competence

Within the context of the PSI *competence* as a construct relating to parent characteristics refers to a parents beliefs regarding their ability to parent their child and the ownership of the necessary skills to carry out parenting tasks (Abidin, 1995). Given the behavioural characteristics of autism described earlier in this thesis many parents feel a sense of helplessness when confronted with difficult or challenging behaviour. (McCubbin et al. 2005). Moreover, given the atypical behaviour of children with autism many parents feel ill equipped to manage such behaviours within the family and are uncertain as to whether to adopt an authoritarian or more accepting parent style (Hastings and Brown, 2002). Analysis of the parent programme suggests that the greatest change in means within the parent domain of the PSI was within the sub-domain competence (appendix 9, p.134). This change implies that some aspect or aspects of the programme enhanced parental appraisals of their ability to appropriately parent their child with autism, and that parents were able to identify aspects of their situation that they could exert some influence over. As discussed, the coping style *confrontive coping* is a problem-focussed coping style which is employed successfully by individuals when they appraise that a situation can be altered in some way and where the individual experiences significant motivation to exert change (Folkman *et al.*, 1986). The parent programme intervention resulted in an increased use of *confrontive coping* as measured by changes in the Ways of coping. In chapter 3 this thesis discussed the concept of *motivational relevance* (Smith and Lazarus, 1993). *Motivational relevance* refers to the extent to which a stressful encounter touches upon personal goals, beliefs and threat to personal wellbeing (Smith *et al.*, 1993). Given that parents have strong attachments to their children, child behaviour has a significant degree of *motivational relevance* and encourages the use of *confrontive coping* styles. However, due to the

degree of stress experienced by parents it would seem appropriate to assert that many parents will feel general exhaustion from previous attempts to try and control their child (Hastings and Brown, 2002). This exhaustion can often leave parents feeling ambivalent about making changes in their life and that of their family, particularly if they have experienced failure in the past (Hastings *et al.*, 2005). Unlike other directive parent-mediated approaches that can add to parent exhaustion (McHugh, Saunders and Reed, 2008), the parent programme utilised Motivational Interviewing techniques to explore parent's motivation to identify those aspects of their child's behaviour that may be open to support and generate socially valid means of implementing support. All of this requires a mixture of problem and emotion focussed coping styles and the increased use of *accepting responsibility* and *confrontive coping* by participants reflects this adaptive style. Moreover, the reduction in stress observed within the *competence* sub-domain of the PSI may also indicate the growing confidence of parents engaged in the programme as they learn success in identifying behaviours' that are receptive to support.

Parental experience of their child is central to deriving meaning from interaction, this in turn influences parental reflection on their own competence of parenting their child. Motivational Interviewing techniques employed within the study sought not to place an external definition on child behaviour, but rather to provide parents with an opportunity to reflect upon their experiences with their child and resolve ambivalent feelings they may have to interaction and expectations of child behaviour. Motivational Interviewing was chosen as a technique, as rather than categorise child behaviour for the parent it allowed them to reflect upon experience and use this as a means to enhance future interaction and feel confident within those interactions.

8.3 Methodology Critique

While the intervention's sample size was large enough to allow for statistical exploration of the data, like many other studies in autism it was still relatively small (Diggle and McConnachie, 2009). This is a general criticism of this area of study, which as has been stated earlier is often attributed to the low incidence of autism. However, the limited sample size was largely due to the limited finances available to

carry the study out and the time resource allocated to the author. As discussed earlier, this also had knock on effects when considering the possibility of a control group. During the design phase the author considered a control group but was aware that this would be at the cost of sufficient numbers of participants given that time and finances would have to be re-allocated to taking measures from a waiting group. However, lack of controls is also noted by researchers in this area of study, and has been attributed to the ethical consideration that it is better to offer parents some form of intervention rather than nothing at all (Diggle and McConnachie, 2009; SIGN, 2007).

While approaches employed within this intervention such as MI and PP have been evaluated within other areas of intervention, with other populations, the parent programme is unique in combining these approaches and delivering this combination to parents of children with autism. Further exploration should be considered of how elements of the intervention such as positive programming, the workshops, the manuals, family facilitator sessions, MI, and manual content contribute to changes in parental stress and coping styles. For example, it would be of interest to know how much of the variance is predicted by the roles of the Family Facilitators when compared to the manuals and workshops. However, this again has resource implications and while the study was given a generous grant there was insufficient resource to involve measures of the Parent Programme components. Future research within this area could then consider the various elements of the study and compare outcomes against one another. For example, research which simply employs MI techniques could be contrasted with studies using other single elements such as the family facilitator sessions or workshops. Findings from such research may reveal elements which are more cost effective and more readily accessible to families and funders. In addition future research should also consider elements of sampling such as; age of child, child ability, age of parents, parental marital status and presence of other siblings within the family. These are important aspects that were not considered within the scope of the intervention described and places limits upon the conclusions which can be drawn.

A more thorough exploration of all coping variables and their relationships to parental stress would have been beneficial. The research identified the coping variables for analysis based on one area of the literature, however, further analysis would have revealed a greater understanding of the relationship between changes in parent stress and the resulting coping styles used. While complex this would have given a sense of insight into the nature of the transactions between parents and stressful encounters, particularly as existential and spiritual dimensions of coping and how they were used by parents did not form part of the intervention.

While comments by parents were taken (appendix10, P.135) this did not follow a systematic qualitative analysis and again had resource been available this would have been a worthwhile enterprise, particularly when we consider the statement above regarding the relationship between parents' experience of stress from caring for their child, the coping styles they use and their adaptability relative to the intervention. Should the study be replicated then this would be an area worth exploring as the insight gained may offer new perspectives into how dependent and independent variables interact.

8.4 Conclusion

The results of the parent programme suggest that parent-mediated interventions that target parental appraisals are efficacious in reducing parental stress. The psycho-educational nature of the intervention described in this thesis seems exempt from inducing stress in parents that is otherwise found in other forms of intervention where parents experience stress through the burden of implementing a set of prescribed techniques with their child. Psycho-educational interventions such as the Triple P Programme (Sanders *et al.*, 2003) have a strong evidence base in reducing parental stress, but they are limited to parents of typically developing children and as well as concerns regarding ethical validity, there is a lack of empirical evidence to support the variation of the Triple P, (Stepping Stones Triple P) which has been developed for parents of children with developmental disorders.

The stress experienced by parents of children with autism is relatively unique and relative to other forms of disability is considered to be excessively high and of a

clinical nature. As such, the notion of a variation of the Triple P, which is designed for parents of children with any developmental disability, may in fact be too broad. However, there is a shared element between the SSTP and parent programme described in this thesis and that is an emphasis on parent appraisal and the coping styles employed in which knowledge seems to play a central role. The picture of interaction between families with children with disabilities and the provision of services to support them is not fixed to a particular point in time post diagnosis, the nature of the interaction is continuous and varies across the life span of the disabled child implying that approaches should be flexible enough to accommodate all ages of children.

Many standard parent-mediated interventions such as ABA pay excessive attention to the early years of development and ignore older children who may in fact be more difficult to manage within the family home and place additional stresses on parents through fear of harm to siblings. The Scottish Government's strategy for children *Getting it Right for Every Child* (Scottish Government, 2006) places significant emphasis on supporting parents and the *circles of support* around the child. The principles and overarching philosophy of this innovative document are to be applauded but there remain significant gaps in our knowledge as to how to deliver the correct supports, which are person and family centred. Moreover, while national guidelines emphasise the importance of intervention that involves parents (SIGN, 2007) there remains a gap between evidence based practice and practice based evidence to inform what intervention, and how it should be delivered.

Since the development, implementation and writing up of the intervention the author has been engaged in exploring other aspects of coping within parents of children with autism and the staff supporting them. In keeping with the philosophical approach of this thesis, the author has been using aspects of acceptance and mindfulness with parents and carers. Mindfulness and acceptance theory, teaches the individual to pay attention to what is occurring within the here and now. By encouraging the individuals to attend to their own physical experiences and allow all thoughts whether they are painful or not to come and go the individual observes less rumination and associated distress. This would seem to have enormous benefits to parents of children with autism not just because of the potential health benefits,

but by attending to the here and now they are then able to attend to the current engagement with their child.

Finally, during the writing of this thesis the author met with parents (n=10) who were currently engaged in a parent-mediated intervention. The average cost to these families was £700 per month, which was being paid for from the family's disposable income. At a time of austerity when families, NHS and local authority budgets are being tightly squeezed we should consider the impact of delivering such programmes on public finances and on family budgets. Many parent-mediated approaches are privately funded which places new demands and stresses on the family. Families will often reach out to a range of interventions as the sense of doing something is better than doing nothing.

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Appendix 1



Queen Margaret University
EDINBURGH



Dear Parent

We are recruiting parents who are not currently involved in any home-based intervention or are themselves receiving any talk-based therapy for stress, for a year long parent programme study, for parents of children with autism. The programme involves attending 2 workshops, receiving 2 manuals based on the workshops and 21 hours of support from a family facilitator who will help you identify those behaviours you find challenging.

The study is supported by the Local Authority but will be delivered and evaluated by the National Autistic Society who have received a Scottish Government grant to carry the study out. Participants will be selected at random from those who complete this form and return to the address provided. We will inform you in writing as to whether or not you have been successful in being selected for the study.

You are welcome to withdraw from the study at any point and any information you provide during the study will only be accessible to yourself and the members of the study team. Personal information will be destroyed at the end of the study period in line with data protection legislation (Data Protection Act, 1998).

Full details of the study aims will be given if you wish to participate and have been selected. Should you wish to be put forward to participate then please fill in the cut off sheet below and return it in the stamped addressed envelope provided which will be forwarded to the researcher. The study is for single parents, married couples and those living with their partner even if they are not related to your son or daughter.

If you do not wish to participate then you need to nothing more and we thank you for taking the time to read this.

Yours Sincerely

Michael McCreadie
(Depute Principal, Support for Learning Daldorch House School & Researcher)

Please tear along here and return

.....

I/We would like to participate in the National Autistic Society Parent Programme study.

Name/s
.....

Address
.....
.....

Appendix 2



Queen Margaret University
EDINBURGH



The National Autistic Society Parent Programme Study Information Sheet

Thank you for agreeing to participate in the parent programme study. The programme is designed for parents of school aged children with autism.

What is the aim of the study?

There are many interventions for children with autism, some of which focus on parents developing particular skills. However, many of the interventions take little or no consideration of the demands that implementing the intervention has on parents and families. Rather than training parents in an approach that is to be used in a prescribed way, this study provides parents with information about autism, assists them in interpreting their child's behaviour and hopefully reduces the overall stress they experience.

How will the study be implemented?

The study involves attending 2 workshops, and receiving 21 hours of support from a family facilitator who will assist you in using a manual to identify behaviours that you wish to address in your child.

The content of the study is as follows:

Attend Workshop 1 & Receive Manual 1

1st visit from Family Facilitator

Attend Workshop 2 & Receive Manual 2

2nd visit from Family Facilitator

Study Results

Data Protection & Confidentiality

The study is designed and developed by Michael McCreadie and will contribute to his doctoral degree in Health Psychology, at Queen Margaret University in Edinburgh. During the study you will be asked to fill in questionnaires on stress and

coping before during and at the end of the study. This will enable the study to be evaluated.

All personal information is confidential and only the researcher and family facilitator will have access to your information, which will be anonymised as part of the study analysis. All personal information at the end of the study will be destroyed.

Study Results

The study is funded by the Scottish Government who will receive a copy of a detailed report of the overall results. An executive summary of the study will be made available and you will receive a copy of this. Each local authority has requested individual feedback on their own area and they will be provided with this in the form of a report. However, this will be overall data and no individual participant information will be shared.

What to do now

All you have to do now is complete and return the consent form enclosed and we will write out to you informing you of where and when the first Workshop will take place with the other participants from your local authority area.

Any other questions?

If you have any other questions, please do not hesitate to contact myself at Daldorch House School.

01290 551666

michael.mccreadie@nas.org.uk

Yours Sincerely

Michael McCreadie
(Depute Principal, Support for Learning Daldorch House School & Researcher)

Appendix 3



Queen Margaret University
EDINBURGH



Dear

We are pleased to inform you that you have been selected for the National Autistic Society Parent Programme. Please read the enclosed information sheet, which provides details of the study and if you are still happy to participate sign and return the consent form below and return in the stamped addressed envelope provided.

Yours Sincerely

Michael McCreadie
(Depute Principal, Support for Learning Daldorch House School & Researcher)

(Please complete, tear off and return)

.....
I/We would like to participate in the National Autistic Society Parent Programme.
I/We have read and understand the information sheet regarding the purpose of the study and consent to our information being held on file for the purpose of the research.

Name/s
.....

Signature/s.....
.....

Date.....

Appendix 4



Queen Margaret University
EDINBURGH



Dear Parent

We are sorry to inform you that you have not been randomly selected to participate in the National Autistic Society Parent Programme Study. As the study has limited funds there is limited availability for parents who wish to be involved in the study. However, we have passed your details on to your local authority who will inform you if any similar studies or programmes are to be delivered in your area.

I wish you all the very best, and thank you for showing interest in the study.

Yours Sincerely

Michael McCreadie
(Depute Principal, Support for Learning Daldorch House School & Researcher)

Appendix 5

Workshop 1 PPT

Appendix 6

Parent Programme

Autism Quiz

	TRUE
Autism is present at or shortly after birth	Y/N
Autism is a mental illness	Y/N
Autism is more common in boys	Y/N
Autism can be cured	Y/N
Autism has a genetic component	Y/N
Autism and Asperger Syndrome are the same thing	Y/N
Siblings of children with Autism are more likely To have difficulties with learning or social understanding	Y/N
Children with autism cannot learn new skills	Y/N
If you have a high IQ you cannot have autism	Y/N
Everyone with autism has a low IQ	Y/N
Children with autism have unusually good hearing	Y/N
Children with Autism cannot understand emotions	Y/N

Appendix 7

Workshop 2 PPT

Appendix 8

Manuals

Appendix 9

Descriptive Statistics PSI Sub Domains

PSI Sub-Domains	N	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
CDDHT1	71	12	43	27.39	7.448	.225	.285	-.652	.563
CD ADT 1	71	16	53	32.35	8.442	.205	.285	-.498	.563
CD RE T 1	71	8	29	21.04	4.630	-.345	.285	-.460	.563
CDDHT1	71	17	44	29.14	7.564	.178	.285	-.837	.563
CDMOT1	71	7	27	18.65	4.290	-.434	.285	-.432	.563
CDACT1	71	9	34	23.13	5.642	-.328	.285	-.119	.563
PDCOT1	71	10	63	30.42	12.356	.591	.285	-.356	.563
PDATT1	71	6	32	21.34	6.208	-.315	.285	-.088	.563
PDHET1	71	1	41	13.52	6.118	1.062	.285	4.548	.563
PDRRT1	71	8	33	22.27	5.784	.034	.285	-.371	.563
PDDPT1	71	9	40	23.42	6.517	.526	.285	.015	.563
PDSPT1	71	6	31	16.51	5.689	.479	.285	-.182	.563
CDDH2	71	5	30	19.59	5.625	-.412	.285	-.063	.563
CDADT2	71	5	51	22.44	6.748	.729	.285	3.690	.563
CDRET2	71	4	29	15.96	4.578	.077	.285	1.122	.563
CDDHT2	71	11	42	20.77	5.777	1.105	.285	2.415	.563
CDMOT2	71	8	28	15.55	4.468	.355	.285	-.334	.563
CDACT2	71	8	27	17.30	4.350	.138	.285	.257	.563
PDCOT2	71	10	38	19.63	6.755	.879	.285	.221	.563
PDATT2	71	6	29	16.37	4.914	.022	.285	-.214	.563
PDHET2	71	3	38	12.34	5.821	1.438	.285	4.598	.563
PDRRT2	71	4	28	16.93	4.370	-.165	.285	.869	.563
PDDPT2	71	4	36	17.58	5.198	.326	.285	1.815	.563
PDSPT2	71	4	27	13.80	5.312	.482	.285	-.057	.563
CDDHT3	71	5	27	16.96	4.477	-.370	.285	.145	.563
CDADT3	71	7	30	18.68	4.417	-.123	.285	-.006	.563
CDRET3	71	6	23	14.42	3.400	-.080	.285	.024	.563
CDDHT3	71	9	27	17.80	4.143	.276	.285	-.492	.563
CDMOT3	71	6	23	14.17	4.199	.044	.285	-.484	.563
CDACT3	71	6	27	15.65	4.293	.378	.285	-.072	.563
PDCOT3	71	7	30	16.72	5.043	.530	.285	-.121	.563
PDATT3	71	7	29	14.28	4.536	.463	.285	.460	.563
PDHET3	71	2	20	10.94	3.817	.013	.285	-.431	.563
PDRRT3	71	4	24	14.89	3.934	-.024	.285	.332	.563
PDDPT3	71	6	24	15.39	3.743	-.140	.285	.122	.563
PDSPT3	71	3	24	12.51	4.545	.112	.285	-.360	.563
PDIST1	71	3	35	19.69	7.072	-.023	.285	-.812	.563
PDIST2	71	3	29	15.69	5.320	.159	.285	-.372	.563
PDIST3	71	3	24	14.00	4.558	.053	.285	-.328	.563

Appendix 10 Pearson and Spearman Correlations

	Tests of Normality					
	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Conf Coping Time 1	.156	71	.000	.950	71	.007
Dist Time 1	.140	71	.002	.941	71	.002
Self Controlling Time 1	.124	71	.009	.982	71	.396
Seek Soc Support Time 1	.106	71	.047	.969	71	.075
Accept Resp Time 1	.128	71	.006	.964	71	.042
Escape Avoid Time 1	.173	71	.000	.907	71	.000
Planful Prob Solving Time 1	.100	71	.077	.975	71	.172
Positive Reappraisal Time 1	.151	70	.000	.963	70	.039
Conf Coping Time 2	.109	71	.037	.967	71	.061
Distancing Time 2	.173	71	.000	.903	71	.000
Self Controlling Time 2	.094	71	.199	.977	71	.213
Seeking Soc Support Time 2	.139	71	.002	.947	71	.005
Accept Resp Time 2	.121	71	.011	.968	71	.064
EScape Avoid Time 2	.136	71	.002	.963	71	.036
Planful Prob Solving Time 2	.100	71	.078	.958	71	.018
Positive Reappraisal Time 2	.181	71	.000	.886	71	.000
Conf Coping Time 3	.142	71	.001	.969	71	.075
Distancing Time 3	.225	71	.000	.896	71	.000
Self Controlling Time 3	.106	71	.047	.962	71	.032
Seeking Social Support Time 3	.113	71	.025	.956	71	.013
accepting Responsibility Time 3	.100	71	.076	.976	71	.179
Escape Avoidance Time 3	.111	71	.029	.959	71	.021
Planful Problem Solving Time 3	.143	71	.001	.956	71	.014
Positive Reappraisal Time 3	.167	71	.000	.947	71	.005
CDDHT1	.098	71	.088	.973	71	.122
CD Adaptability time 1	.078	71	.200 ⁺	.979	71	.272
CD reinforces parent time 1	.145	71	.001	.958	71	.019
CDDT1	.084	71	.200 ⁺	.956	71	.015
CDMOT1	.131	71	.004	.967	71	.057
CDACT1	.072	71	.200 ⁺	.981	71	.364
PDCOT1	.121	71	.012	.957	71	.016
PDIST1	.099	71	.085	.975	71	.175
PDATT1	.098	71	.088	.970	71	.090
PDHET1	.088	71	.200 ⁺	.927	71	.000
PDRRT1	.083	71	.200 ⁺	.975	71	.174
PDDPT1	.099	71	.085	.968	71	.067

PDSPT1	.135	71	.003	.967	71	.062
CDDH2	.120	71	.013	.976	71	.193
CDADT2	.078	71	.200*	.946	71	.004
CDRET2	.095	71	.182	.973	71	.122
CDDDET2	.133	71	.003	.929	71	.001
CDMOT2	.114	71	.022	.973	71	.135
CDACT2	.122	71	.010	.969	71	.081
PDCOT2	.110	71	.034	.927	71	.000
PDIST2	.122	71	.010	.980	71	.324
PDATT2	.115	71	.022	.981	71	.359
PDHET2	.141	71	.001	.900	71	.000
PDRRT2	.092	71	.200*	.975	71	.167
PDDPT2	.081	71	.200*	.970	71	.089
PDSPT2	.119	71	.014	.971	71	.100
CDDHT3	.123	71	.009	.979	71	.279
CDADT3	.085	71	.200*	.987	71	.673
CDRET3	.070	71	.200*	.991	71	.884
CDDDET3	.103	71	.061	.974	71	.151
CDMOT3	.085	71	.200*	.980	71	.334
CDACT3	.072	71	.200*	.979	71	.296
PDCOT3	.084	71	.200*	.970	71	.085
PDIST3	.092	71	.200*	.985	71	.584
PDATT3	.095	71	.186	.963	71	.034
PDHET3	.089	71	.200*	.987	71	.659
PDRRT3	.110	71	.032	.980	71	.321
PDDPT3	.087	71	.200*	.982	71	.405
PDSPT3	.108	71	.040	.983	71	.454

a. Lilliefors Significance Correction

*. This is a lower bound of the true significance.

Pearson Correlation Time 1

Pearson Correlation Time1		CDDH	CD A	CDRP	CDDE	CDM O	CDAC T	PDCO	PDIS	PDAT	PDHE	PDRR	PDD P	PDSP
CC	Pearson Correlatio n	.075	.090	-.031	-.129	-.100	-.040	.055	-.150	.124	-.118	-.028	.095	.193
	Sig. (2- tailed)	.536	.456	.797	.284	.405	.739	.646	.211	.304	.325	.817	.429	.107
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
D	Pearson Correlatio n	.023	- .044	.018	-.109	-.075	-.209	-.106	-.175	-.011	-.104	.133	- .073	.064
	Sig. (2- tailed)	.851	.713	.879	.367	.535	.081	.378	.143	.926	.387	.270	.543	.596
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
SC	Pearson Correlatio n	.153	.132	.099	.202	.091	.116	.170	.149	.177	-.279*	.186	.230	.202
	Sig. (2- tailed)	.202	.273	.412	.091	.449	.335	.156	.215	.141	.019	.120	.053	.092
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
SSS	Pearson Correlatio n	-.090	- .105	-.066	-.165	.074	-.058	-.118	-.106	.075	-.204	.055	.053	.038
	Sig. (2- tailed)	.454	.382	.583	.170	.540	.630	.328	.380	.532	.088	.651	.664	.753
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
AR	Pearson Correlatio n	.375**	.192	.003	.101	.180	.121	.278*	.253*	.056	.005	.088	.076	.350**
	Sig. (2- tailed)	.001	.109	.978	.404	.132	.313	.019	.033	.640	.967	.464	.527	.003
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
EA	Pearson Correlatio n	.189	.029	-.040	.005	.162	.140	.210	.055	.099	-.121	.124	.170	.142
	Sig. (2- tailed)	.115	.810	.740	.970	.177	.245	.078	.649	.412	.313	.302	.157	.239
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
PPS	Pearson	.058	.132	-.135	-.010	-.032	-.007	-.074	-.065	.132	-.417**	.238*	.071	.034
	Sig. (2- tailed)	.628	.274	.262	.934	.794	.951	.537	.590	.273	.000	.046	.559	.780

PR	Pearson	-.100	-.125	.079	-.050	.003	.028	-	-.051	.077	.067	-.006	-.115	-.057
	Correlation							.243*						
	Sig. (2-tailed)	.405	.299	.513	.681	.978	.814	.041	.672	.522	.581	.960	.339	.638
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
	Sig. (2-tailed)	.001	.408	.107	.512	.051	.035	.220	.285	.479	.374	.283	.009	
	N	71	71	71	71	71	71	71	71	71	71	71	71	71

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Pearson Correlation Time 3

						CDM	CDAC							
		CDDH	CDA	CDRP	CDDE	O	T	PDCO	PDIS	PDAT	PDHE	PDRR	PDDP	PDSI
CC	Pearson	.063	.050	.040	-.065	-.136	.096	-.282 [*]	.021	.140	.194	-.091	-.107	-.07
	Correlation													
	Sig. (2-tailed)	.600	.676	.739	.591	.258	.424	.017	.861	.244	.105	.450	.373	.55
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
D	Pearson	.134	.049	-.002	-.081	-.280 [*]	-.059	-.154	-.246 [*]	-.105	.109	-.043	-.112	.22
	Correlation													
	Sig. (2-tailed)	.265	.687	.990	.502	.018	.626	.200	.039	.382	.364	.720	.353	.05
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
SC	Pearson	.150	.154	.184	.084	-.014	.026	.128	.107	.149	-.063	.197	.310 ^{**}	-.10
	Correlation													
	Sig. (2-tailed)	.211	.199	.125	.486	.908	.829	.289	.375	.215	.603	.099	.009	.40
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
SSS	Pearson	-.062	.066	-.105	-.193	-.030	.089	-.044	-.124	.219	.016	-.057	.045	-.18
	Correlation													
	Sig. (2-tailed)	.607	.586	.384	.107	.805	.462	.715	.302	.067	.895	.639	.712	.13
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
AR	Pearson	.094	.168	.065	.099	-.070	-.017	.047	.191	.134	.040	.138	.302 [*]	-.03
	Correlation													
	Sig. (2-tailed)	.437	.162	.589	.413	.563	.887	.695	.110	.264	.738	.252	.010	.75
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
EA	Pearson	.293 [*]	.107	-.211	-.254 [*]	.102	.265 [*]	.022	.108	.264 [*]	.048	.101	.101	-.13
	Correlation													
	Sig. (2-tailed)	.013	.376	.078	.033	.397	.025	.857	.368	.026	.688	.400	.400	.27
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
PPS	Pearson	.134	.009	.097	-.048	-.091	.168	-.226	.182	.154	-.263 [*]	.143	.029	.02
	Correlation													
	Sig. (2-tailed)	.267	.938	.419	.691	.453	.162	.058	.129	.201	.027	.236	.812	.87
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
PR	Pearson	.141	.038	.134	-.085	-.007	.150	-.109	.217	.097	-.025	.095	.001	-.07
	Correlation													
	Sig. (2-tailed)	.242	.755	.265	.480	.957	.211	.367	.070	.422	.833	.432	.993	.53
	N	71	71	71	71	71	71	71	71	71	71	71	71	7
	Sig. (2-tailed)	.400	.880	.129	.964	.678	.379	.380	.207	.162	.859	.629	.966	
	N	71	71	71	71	71	71	71	71	71	71	71	71	7

Spearman's Correlation Time 1

*. Correlation is significant at the 0.05 level (2-tailed). **. Correlation is significant at the 0.01 level (2-tailed).

			CDD H	CDA CDA	CDR P	CDD E	CD MO	CDA CT	PDCO	PDIS	PDA T	PD HE	PDR R	PD DP	PDSP
Spearman's rho	CC	Correlation Coefficient	.067	.086	-.032	-.118	- .122	-.056	.040	-.148	.087	- .088	-.031	.082	.173
		Sig. (2-tailed)	.578	.478	.791	.328	.309	.643	.739	.217	.473	.465	.798	.495	.150
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	D	Correlation Coefficient	.011	-.072	.021	-.104	- .087	-.164	-.140	-.209	.012	- .049	.109	-	.101
		Sig. (2-tailed)	.930	.553	.862	.386	.472	.173	.244	.080	.920	.685	.367	.754	.401
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	SC	Correlation Coefficient	.141	.096	.097	.184	.120	.103	.160	.151	.146	- .229	.174	.245	.226
		Sig. (2-tailed)	.242	.424	.421	.125	.317	.395	.183	.208	.226	.055	.146	.039	.058
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	SSS	Correlation Coefficient	-.098	-.080	-.054	-.137	.039	-.063	-.058	-.084	.115	- .200	.101	.066	.056
		Sig. (2-tailed)	.417	.508	.654	.255	.749	.602	.633	.486	.339	.095	.401	.586	.645
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	AR	Correlation Coefficient	.320**	.223	-.003	.108	.168	.102	.213	.243*	.046	.098	.072	.104	.347**
		Sig. (2-tailed)	.007	.062	.983	.370	.162	.398	.075	.041	.703	.414	.552	.388	.003
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	EA	Correlation Coefficient	.180	.025	.000	.021	.139	.099	.217	.013	.004	- .099	.123	.175	.112
		Sig. (2-tailed)	.133	.838	.998	.865	.249	.413	.069	.913	.975	.413	.306	.144	.354
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	PPS	Correlation Coefficient	.064	.133	-.122	-.010	- .076	.016	-.074	-.051	.151	- .376	.208	.101	.052
		Sig. (2-tailed)	.598	.270	.309	.934	.530	.898	.538	.672	.210	.001	.082	.404	.669
		N	71	71	71	71	71	71	71	71	71	71	71	71	71

Spearman's Correlation Time 2

			CDD H	CDA	CDR P	CDD E	CDM O	CDA CT	PDC O	PDIS	PDA T	PDH E	PDR R	PD DP	P D S P
Spearman's rho	CC	Correlation Coefficient	-.189	-.081	.030	-.033	-.108	-.051	-.310**	-.060	-.082	.068	.047	-.104	-.115
		Sig. (2-tailed)	.115	.504	.802	.782	.372	.672	.008	.619	.496	.575	.694	.386	.339
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	D	Correlation Coefficient	-.019	.025	-.117	-.081	-.230	-.114	-.061	-.203	-.097	.159	-.011	-.041	.011
		Sig. (2-tailed)	.874	.839	.330	.503	.053	.345	.612	.089	.422	.185	.927	.737	.928
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	SC	Correlation Coefficient	.148	.100	.202	.160	.041	.111	.037	.121	.052	-.095	.294*	.215	-.078
		Sig. (2-tailed)	.218	.408	.092	.182	.735	.357	.762	.316	.668	.429	.013	.072	.518
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	SSS	Correlation Coefficient	-.212	-.070	-.048	-.101	-.090	-.098	-.273*	-.055	.017	-.080	-.093	-.135	-.130
		Sig. (2-tailed)	.076	.561	.689	.403	.457	.415	.021	.650	.888	.506	.441	.261	.279
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	AR	Correlation Coefficient	.125	.025	.115	.190	.026	.024	-.067	.197	.008	.050	.223	.131	-.038
		Sig. (2-tailed)	.300	.836	.340	.113	.831	.844	.577	.099	.944	.679	.062	.275	.753
		N	71	71	71	71	71	71	71	71	71	71	71	71	71
	EA	Correlation Coefficient	.082	.057	-.182	-.145	.003	.201	.031	.015	-.048	.095	.173	.097	-.058
		Sig. (2-tailed)	.496	.636	.128	.229	.983	.093	.799	.903	.692	.429	.150	.422	.629
		N	71	71	71	71	71	71	71	71	71	71	71	71	71

PPS	Correlation Coefficient	-.093	-.020	.079	.087	-.149	.027	-.261*	.125	.024	-.208	.080	-.077	.018
	Sig. (2-tailed)	.442	.869	.511	.472	.216	.823	.028	.299	.842	.082	.507	.526	.884
	N	71	71	71	71	71	71	71	71	71	71	71	71	71
PR	Correlation Coefficient	-.064	-.057	.143	-.019	.016	.016	-.226	.016	.079	-.050	.102	-.111	-.121
	Sig. (2-tailed)	.598	.635	.233	.877	.894	.893	.058	.893	.511	.678	.398	.357	.314
	N	71	71	71	71	71	71	71	71	71	71	71	71	71

Spearman's Correlation Time 3

				CD	CDR	CDD	CDM	CDA	PD		PDA		PDR		
			CDDH	A	P	E	O	CT	CO	PDIS	T	PDHE	R	PDDP	PDSP
Spearman's rho	CC	Correlation Coefficient	.060	.035	.025	-.061	-.144	.092	-	.003	.137	.171	-.099	-.164	-.049
									.290						
		Sig. (2-tailed)	.622	.774	.838	.611	.229	.445	.014	.983	.256	.154	.412	.173	.687
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	D	Correlation Coefficient	.205	.078	-.065	-.052	-	-.028	-	-.251 [*]	.012	.084	-.053	-.084	.239 [*]
							.306 ^{**}		.084						
		Sig. (2-tailed)	.087	.520	.590	.668	.010	.818	.487	.035	.918	.487	.663	.488	.045
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	SC	Correlation Coefficient	.107	.152	.146	.058	-.057	.037	.049	.067	.134	-.061	.231	.308 ^{**}	-.084
		Sig. (2-tailed)	.375	.206	.226	.631	.634	.761	.685	.577	.264	.616	.053	.009	.488
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	SS	Correlation Coefficient	-.076	.070	-.078	-.141	-.043	.088	-	-.125	.181	-.039	-.043	.063	-.193
									.026						
		Sig. (2-tailed)	.526	.562	.519	.240	.721	.466	.831	.301	.132	.744	.719	.600	.107
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	AR	Correlation Coefficient	.088	.155	.057	.108	-.079	.005	.047	.190	.127	.045	.158	.224	-.035
		Sig. (2-tailed)	.465	.198	.637	.370	.513	.966	.697	.112	.291	.707	.189	.061	.770
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	EA	Correlation Coefficient	.296 [*]	.178	-.207	-.257 [*]	.032	.278 [*]	-	.120	.189	.106	.067	.063	-.076
								.017							
		Sig. (2-tailed)	.012	.138	.083	.031	.790	.019	.890	.319	.114	.381	.577	.604	.531
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	PP	Correlation Coefficient	.090	.009	.128	-.035	-.107	.176	-	.169	.130	-.255 [*]	.172	.026	-.004
									.271						
		Sig. (2-tailed)	.454	.941	.286	.769	.375	.141	.023	.159	.282	.032	.153	.828	.975
	N		71	71	71	71	71	71	71	71	71	71	71	71	71
	PR	Correlation Coefficient	.134	.072	.160	-.073	-.053	.126	-	.215	.123	-.059	.130	.070	-.067
									.063						
		Sig. (2-tailed)	.266	.552	.182	.544	.658	.297	.600	.071	.307	.625	.278	.564	.580
	N		71	71	71	71	71	71	71	71	71	71	71	71	71

Key to variables in correlation tables

Ways of Coping

CC = Confrontive Coping
D= Distancing
SC=Self Controlling
SSS=Seeking Social Support
AR= Accepting Responsibility
EA= Escape Avoidance
PPS=Planful Problem Solving
PR=Positive Reappraisal

PSI Subdomains

Child
CDDH= Hyperactivity
CDA= Adaptability
CDRP=Reinforces Parent
CDDE=Demandingness
CDMO=Mood
CDACT=Acceptability

Parent

PDCO=Competence
PDIS=Isolation
PDAT=Attachment
PDHE=Health
PDRR=Role Restriction
PDDP=Depression
PDSP=Spouse

Appendix 11

Parental Comments on Workshops

It was commented by participants that they enjoyed the opportunity to liaise with other parents. When asked what aspects of the session they found most useful, many commented that it was beneficial hearing *“personal examples as it is nice to know that all people are in the same boat.”* Another attendee/participant stated that they enjoyed *“meeting different families going through the same stuff as us.”*

When asked to rate how useful the references made to the examples used throughout the workshops were, 96% of attendees/participants considered them to be excellent or above average. 96% considered that by attending Workshop 1 they had developed their understanding of behaviour. 53% of attendees/participants believed that the course had developed their knowledge of how to manage behaviour to an excellent standard with a further 36% rating their knowledge as above average at the end of the session. 98% of participants stated that the overall rating of the course was excellent or above average. 57% of attendees/participants commented at the end of Workshop 1 that they gained a further understanding of autism spectrum disorder. Many parents/carers shared that they were hoping to understand more about their child's behaviour which was felt by many to have been achieved. One parent/carer explained they had hoped *“to understand why their son behaved in certain ways and these were met.”* Another individual stated that they *“didn't think it would help but they got lots of help and practical ideas.”* *“it was good to be in the company of other parents and listen to their experiences.”* One participant commented that *“the workshop was delivered in a very accessible manner.”* One participant stated that they found the *“sharing of experiences very useful and appreciated the time taken to discuss individual problems and the advice give.”*

Family Facilitator Support

With regard to Family Facilitator input, a number of participants stated that they felt they got a lot from their support. They stated that they found the facilitators empathic and non-judgemental. One parent stated that they were *“different from the condescending support they had been offered in the past.”* One family shared that the Family Facilitator brought the family into a uniform way of thinking.

It was commented by participants that Family Facilitators were understanding and demonstrated excellent listening skills. It was commented on by one participant that the facilitator offered their family *“excellent advice on the matters that I have been working on and has also allowed my confidence to grow in knowing that I am handling the situation as best as I can.”* It was stated that the facilitators were *“approachable and had a general knowledge of autism. I feel I could ask her anything.”* Many families commented that they valued the chance to chat with someone on a one to one basis and bounce ideas off each other. One family made comment how they appreciated the visits being at home which meant they didn't have to worry about childcare. Several families commented on how the visits led to them as a couple to focus their discussion.

Appendix 12

List of Abbreviations

ABA	Applied Behaviour Analysis
DTT	Discrete Trial Training
NAS	National Autistic Society
PP	Positive Programming
PSI	Parenting Stress Index
PRT	Pivotal Response Training
SRP	Son-Rise Programme
SSTP	Stepping Stones Triple P
TEACCH	Treatment and Education of Autistic and related Communication- handicapped Children
WoC-R	Ways of Coping Revised